The Perceptions of Children with Congenital Heart Disease in Saudi Arabia and Parents' Proxy Reports about the Children's Behavioural and Emotional Status:

A Grounded Theory Study

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Acknowledgements

Abstract

Background: Even with a recent improvement in survival and prevalence rates of children with congenital heart disease (CHD) worldwide, CHD in children remains a global burden. A high incidence rate of children with CHD in Saudi Arabia (SA) indicates a need for attention to be paid to this population. A literature review was conducted following a systematic process, revealed that children with CHD exhibit behavioural and emotional issues due to undergoing different medical treatments and hospitalisation. There is a lack of in-depth exploration of the behaviour and emotions of children with CHD through qualitative research, and limited understanding of the self-perceptions of children younger than seven-year-old.

Aim: To explore the behaviour and emotions of 4-10 years old with CHD in SA, through children's self-perception and parental proxy reports.

Methods: Constructivist Grounded Theory (GT) approach of Charmaz was used. Twenty semi-structured interviews of ten child/parent dyads were undertaken. Children's interviews were combined with an Arts-Based approach using drawing, pictures, and faces of emotions (emojis).

Findings: The perceptions of children and parents were conceptualised into a core category *the behavioural and emotional reactions to stressful events related to living with CHD*, and three sub-categories: *CHD medical treatment stressors*, *sociocultural stressors,* and *physical changes stressors.* A substantive theory emerged, identified as *children's behavioural and emotional reactions towards stressors related to living with CHD with the presence of influencing factors.*

Conclusion: The findings from this study contribute to the understanding of relationships between CHD and children's behavioural and emotional reactions. Also, they supported the need for early assessment of behaviour and emotions among children with CHD, and the application of preventative and supportive measures for the children and their families in SA.

Table of Contents

List of Tables:

List of Figures:

List of Pictures:

Abbreviations

AHA: American Heart Association

ASD: Atrial Septal Defect

BPS: Biopsychosocial model

CBC/CBCL: Child Behavioural Checklist

CDC: Center for Disease Control and Prevention

CHD: Congenital Heart Disease

COVID-19: Coronavirus disease of 2019

CRD: The Centre for Reviews and Dissemination

CYP: Children and Young People

DILV: Double inlet left ventricle

FST: Family systems theory

FSA: Family systems approach

FSN: Family systems nursing

GAS: General adaptation syndrome

GT: Grounded Theory

GUCH: Grown Up with Congenital Heart Disease

ICQ: Infant Characteristics Questionnaires

ITSEA: Infant Toddler Social and Emotional Assessment

KAUH: King Abdulaziz University Hospital

LVOT: Left ventricular outflow tract

MMAT: Mixed Methods Appraisal Tool

MoH: Ministry of health

NCB: National Children's Bureau

NHS: National Health Service

OPC: Paediatric outpatients clinic

PA: Pulmonary atresia

PEO: Population, Exposure, and Outcome format

PIS: Participant information sheet

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis

PS: Pulmonary Stenosis

PTSS: Post-traumatic stress symptoms

RAM: Roy's adaptation model

SA: Saudi Arabia

SHREC: School of Healthcare Research Ethics Committee

TGA: Transposition of the great arteries

TOF: Tetralogy of Fallot

TTSC: Transactional theory of stress and coping

UOL: University of Leeds

UNCR: The United Nations Convention on the Rights of the Child

UNICEF: The United Nations International Children's Emergency Fund

VSD: Ventricular Septal Defect

WHO: World Health Organization

YSR: Youth Self-report

Glossary:

Term	Definition
Congenital heart disease (CHD)	Is the most common type of birth defects where the structure and function of the heart is disturbed. It can affect the blood flow and circulation in the new born baby (CDC, 2020b).
Behavioural and emotional problems	Behavioural problems refer to any persistent behaviour that is diverted from the expected child's developmental stage (e.g. aggressiveness and disobedience) (Ogundele, 2018). Emotional problems can involve expressions of sensations, such as fear and anxiety, that indicate someone having a meaning or sensation of something (Solomon, 2021).
Somatic complaints	Somatic complaints is a psychological term referring to symptoms such as, pain and fatigue, which may or may not be associated with a medical condition (Henningsen, 2019).
Stressors	Stressors are factors which a person can experience from any life changes that involve possible challenges, burden, harm or pressure (Wheaton and Montazer, 2010).

Mediators	Mediators are variables that have facilitating effect on other variables (Holmbeck, 1997; Tsang, 2015).
Moderators	Moderators are the factors that influence the direction and strength of the relationship between two variables (Holmbeck, 1997; Tsang, 2015).

Chapter 1 Introduction

1.1 Introduction

This thesis focuses on exploring the behaviour and emotions of children with congenital heart disease (CHD) in Saudi Arabia (SA). This chapter presents an introduction regarding what CHD is, a description of the population of children with CHD globally and in SA and the importance of exploring the behaviour and emotions in children with CHD. Then, the researcher's interest in conducting this study is described. Finally, the structure of this thesis is outlined.

1.2 Congenital heart disease (CHD)

Cardiovascular diseases, including CHD, were identified as a global burden, with an estimate of 17.8 million deaths globally in 2017 (Haro Abad et al., 2018). A recent data analysis by Zimmerman et al. (2020) demonstrated that the CHD global rate of CHD is 1.8 cases per 100 live births. Fortunately, this data analysis demonstrated that between 1990 and 2017, children's global death rates caused by CHD had declined by 34.5 % (39.7% per 100,000 infants), and the global survival rate of children living with CHD had increased by 18.7 % in 2017. This improved, yet still low, survival rate indicates that CHD is still recognized as a global issue (Zimmerman et al., 2020).

In SA, a systematic review conducted in 2015 reported a CHD incident rate of 2.1 to 10.7 per 1000 persons (Alenezi et al., 2015). Another study found a higher prevalence rate of 14.8 CHD cases per 1000 live births in SA from 2010 to 2013; these rates were reported to be higher than those in other countries in the Middle East (Majeed-Saidan et al., 2019). Moreover, several studies revealed that CHD is more common in male children than female in

SA (Abbag, 1998; Abdulaziz et al., 2020; Al-Wather and Munibari, 2013). Furthermore, the Ministry of Health (MoH) in SA has reported that cardiovascular diseases, including CHD, form 42% of the causes of death in SA (MoH, 2013). The Center for Disease Control and Prevention (CDC) reported that CHD is one of the top ten causes of death in the Saudi Arabian population (CDC, 2020a). The identified high prevalence rate of CHD among children in SA indicates the significance of drawing attention to this specific population to improve the delivery of care and promote the psychosocial support of children who survive CHD into adulthood.

To define CHD, it is described as defects in the heart that present at birth and affect its natural function. These defects appear when the normal heart development at foetal stage is interrupted which can be related to maternal reasons (e.g. alcohol consumption or smoking), or due to chromosomal and genetic alterations (e.g. Down syndrome) (NHS, 2021). CHD is classified into cyanotic and a-cyanotic CHD. Cyanotic CHD (e.g. Transposition of Great Arteries) usually manifests as blue lips and nails because of the low oxygen saturation levels, where immediate diagnosis and correction of CHD are vital. On the other hand, a-cyanotic CHD is characterised by obstructions or septal defects (e.g. ventricular septal defect) which sometimes can be naturally resolved without treatment. However, in the case of large septal defects, early intervention and surgical corrections are considered an emergency (Rohit and Shrivastava, 2018).

The severity and type of CHD are responsible for the presentation of signs and symptoms. Some children and young people (CYP) show a range of symptoms such as bluish lips, rapid breathing and fatigue when feeding, whereas others have no or only a slight degree of symptoms (CDC, 2020b). Living with CHD requires regular follow ups with doctors for any progress or development of complications (NHS, 2021). Whereas some children with CHD need no invasive treatments and the defect can be treated on its own, others with CHD

need additional surgical operations or invasive treatments, depending on the severity and type of CHD (CDC, 2020b; NHS, 2021). With advances in CHD management and treatment procedures, recent studies in children with CHD have focused more on improving the quality of life of these children (Reiner et al., 2019; Sun et al., 2021) including exploring their psychosocial status (Abda et al., 2019; Hu et al., 2020). These recent studies suggest a shift of focus towards improving psychosocial status, comprising behavioural and emotional, psychological, and social outcomes of children with CHD. Moreover, a report by CDC (2020b) showed that children with CHD, compared to healthy children, are prone to developing developmental, psychological, and behavioural problems or impairments. The need for exploring the behaviour and emotions of children with CHD is now elaborated upon.

1.3 Significance of studying the behaviour and emotions of CYP with CHD:

Any prolonged and repetitive behaviour that is beyond the expected child's developmental stage and age can be identified as a challenging behaviour or behavioural problem, such as bodily impulsiveness, aggressiveness, disobedience, or fighting (Ogundele, 2018). Emotions are about the combination of sensations and conscious experiences which indicate a meaning of a situation, or a state to a person (Solomon, 2021). Emotional reactions in children can involve fear, anxiety, social phobia, or depression (Ogundele, 2018). CYP from a very early age not only recognize their own emotions; they express them, adapt to and cope with them, and progressively become able to understand and react with less emotional problems towards others' emotions (Smith et al., 2015).

CYP normally experience challenges throughout their lives. They can be affected by several life or health circumstances that may contribute to serious behavioural problems, which interfere with their normal development,

socialisation, or future life. Such behaviours, as identified by the Royal College of Psychiatrists (RCPSYCH), include aggressive or destructive behaviour, or temper tantrums (RCPSYCH, 2021). In addition, children's emotional and behavioural reactions can be affected by external and internal influences, such as confronting family issues or experiencing physical disabilities, which can lead to impairments in their wellbeing and normal development (Weitzman and Wegner, 2015).

Having a long-term condition was found to be a risk factor for developing behavioural and emotional problems in children (Hysing et al., 2009). Hospitalisation due to illness can be a contributing factor to children's behavioural and emotional problems, as it was found that children in hospital can experience emotions such as fear and concerns related to hospital's unfamiliar environment and separation from family (Coyne, 2006). Similarly, CYP with CHD, due to their medical and surgical interventions throughout the treatment plan, can also experience an impact on their behavioural and emotional status. Some studies have revealed evidence of behavioural and emotional issues such as depression and social withdrawal (Guan et al., 2014) among CYP diagnosed with CHD, and a high incidence of emotional reactivity (Larsen et al., 2010). A systematic review reported that a significant number of children with CHD, who had undergone cardiopulmonary bypass surgery, later presented with psychological maladjustment (Latal et al., 2009). These findings emphasise the significance of understanding the behavioural and emotional status of CYP with CHD in order to prevent the impact of living with CHD on CYP's behavioural and emotional status. Further exploration of the literature related to CHD and the behaviour and emotions of children is presented in the next chapter.

1.4 Researcher's interest in the research topic

The interest of the researcher to explore the behaviour and emotions of children with CHD was driven by her experience as a child health nurse, and

caring for children with CHD in SA. Since the researcher observed changes in some children's behavioural and emotional reactions during hospitalisation for CHD management, such as frequent crying, anxiety, and anger, she had developed an interest in understanding the development of these behavioural and emotional reactions in the children.

As it was relevant to identify the required nursing care for these children, the researcher wanted to know how they developed these behavioural and emotional changes, and whether or not these changes were related to living with CHD and/or hospitalisation, or other factors. This interest motivated her to conduct this study from the perspective of the children as well as their parents. The researcher has a keen interest in listening to children's voices and advocating for their voices to be heard. She was curious about how much the children knew about their behavioural and emotional changes, how they felt about having CHD and how they behaved when they knew about CHD, including if they underwent surgery. She wanted to explore how other people treated them when they displayed changes in their behaviour and emotions; how parents perceived their children's behaviour and emotions, and whether their family and friends were supportive and compassionate towards them.

Accordingly, the researcher was motivated to seek answers to these questions from the children themselves and their parents by conducting this study which provides a baseline of information about the behaviour and emotion of children in SA. This study also delivers an in-depth exploration of how children living with CHD can develop behavioural and emotional changes. There was potential to improve nursing care, and include psychosocial support according to the identified needs of the children with CHD and their families. Furthermore, it was considered that by conducting this study it would inform healthcare providers (e.g. cardiologists and nurses) about the behavioural and emotional changes among children with CHD to enhance the medical and nursing care delivery and implement the necessary assessments. In addition,

when exploring the Saudi Arabian literature around children with CHD, a previous study reported a lack of investigations of the psychosocial status of children with CHD and thus identified a need for future research (Almesned et al., 2013).

Therefore, this thesis reports on the first in-depth study that aimed to explore the behaviour and emotions of children with CHD in SA through their self-perceptions and their parents' proxy reports. The researcher believes that because parents are the primary caregiver for children, obtaining parents' reports can add to the understanding of children's behaviour and emotions. Enhancing awareness about children's behaviour and emotion can contribute to improving health care delivery to children with CHD in SA, and to the development of appropriate supportive and preventative measures for families of children with CHD. As a result of this interest, the researcher believes that there is a recognised need to investigate the behavioural and emotional changes in children with CHD, based on her observations when caring for children with CHD, and by the recommendations of a review of Saudi Arabian studies by Almesned et al. (2013) which advocated the exploration of the psychosocial status of children with CHD in SA.

1.5 Thesis structure: chapter outlines

This thesis includes 11 chapters that present this study in a systematic structure.

Chapter 1 introduces the study and sets the study in context, describing the prevalence and incidence rates of CHD globally and in SA. The significance of studying the behaviour and emotions of children with CHD is discussed. Also, the researcher's interest in conducting this study is presented.

Chapter 2 reviews the international literature around children and young people with CHD and their behavioural and emotional status. Using a systematic approach to identifying, reviewing and synthesising the reviewed

studies, the findings are presented within three narrative categories, *identified behavioural and emotional issues in CYP with CHD, relationships between age and gender and the behavioural and emotional issues in CYP with CHD,* and *children developing behavioural and emotional issues related to the CHD complexity and treatment severity.* The review reveals significant research gaps such as a complete lack of qualitative studies exploring the behavioural and emotional status of young children with CHD (younger than 7 years old).

Chapter 3 describes the methodology used in this study. The selection of qualitative research is discussed. Five common approaches of qualitative inquiry are explored against the aim of the current study and the choice of Charmaz's approach to Grounded Theory methodology is justified. The chapter further briefly explains the procedures and processes of conducting a Grounded Theory study.

Chapter 4 demonstrates the methods and steps followed in conducting this study using a constructivist Grounded Theory approach. Participant identification and approaches are explained, followed by a description of the sampling procedures. Moreover, face-to-face interviews as a data collection method for children and parents are described. The conduct of children's interviews is described, combined with a child friendly, Arts-Based approach. Then, the data analysis procedures that were followed are explained. Finally, ethical considerations for conducting this study are discussed.

Chapter 5 presents an introduction to the findings and the characteristics of the study's participants. The chapter also describes the process of generating sub-categories and the core category.

Chapters 6,7,8, and 9 present the findings of each sub-category in separate chapters. The sub-categories indicate the stressors that children with CHD were found to face in this study. These sub-categories are *CHD medical treatment stressors*, *psychosocial and daily life stressors*, and *physical*

changes stressors. The findings regarding the underlying concepts of the sub-categories are described in chapters 6,7, and 8. For example, in chapter 6, the sub-category of *CHD medical treatment stressors* includes the underlying concepts of *CHD correcting procedures*, and *hospital admissions or visits*. Chapter 9 presents the influencing factors that affect the way the children face the stressors and exhibit behavioural and emotional reactions.

Chapter 10 presents the emergent substantive theory. The relationships between the stressors and the influencing factors are presented in a flow chart. The theory is identified as *children's behavioural and emotional reactions towards stressors related to living with CHD with the presence of influencing factors*. The chapter also describes the relationships between the stressors of having CHD and the behaviour and emotions of children.

Chapter 11 discusses the findings in relation to the existing literature. The chapter, then, discusses the current substantive theory by reference to existing theories. Recommendations for future research and implications for practice are also presented, followed by a description of the study's strengths and limitations. Finally, concluding remarks of this thesis are presented.

Chapter 2 Literature Review

2.1   Introduction

This chapter presents a review of the literature around the behaviour and emotions of children and young people (CYP) with CHD and their parents' proxy reports. It was important to evaluate and understand the existing knowledge about the behaviour and emotions of children with CHD. By reviewing the literature, the researcher was able to identify gaps and/or recommendations from previous studies for future research, which facilitated planning the current research while addressing these gaps. This review was conducted initially to refine the research question in this thesis; an earlier version of the review, led by the author of this thesis, has been published (Dahlawi et al., 2020). This chapter restates the published review's methods, and results. The review's search strategy was also revisited a year after the publication, and the description of rerunning the search is also presented in this chapter.

2.2   Review aim, objectives, and question

The aim of this literature review was to understand and evaluate current international literature about the behavioural and emotional status of CYP with CHD with the following objectives:

- to explore the range of behavioural and emotional issues of CYP with CHD;
- to explore CYP's own perceptions about their behaviours and emotions, and their parents proxy reports about their children's behaviour and emotions;

- to identify what research is required to enhance healthcare providers' knowledge and practice concerning the behaviour and emotions of CYP with CHD.

The question guiding this review was: "What is the impact of having CHD on the behaviour and emotions of CYP?"

2.3 Review methods

The review followed the University of York Centre for Reviews and Dissemination CRD (2009) stages: (1) developing the review question, a search strategy and defining inclusion and exclusion criteria; (2) elaborating the research evidence including conducting a thorough search; (3) selecting studies; (4) extracting data; (5) assessing the quality of the reviewed studies; (6) synthesizing the data and (7) disseminating the review. A systematic review was not used because this review explored all studies meeting the criteria, including studies assessed as low-quality. Involving best quality studies is one vital feature of conducting a Systematic Review as suggested by CRD guidelines (CRD, 2009). However, a systematic process informing the literature was followed. This review did not exclude low quality studies, as it was important to identify the weaknesses of all included studies in order to avoid replicating the same errors in this study. Moreover, it can be argued that low quality studies can reveal valuable evidence if the appropriate quality appraisal tool was properly utilised (Pawson, 2006; Riley et al., 2021). Thus, the researcher pursued conducting this literature review by reviewing all possible studies including low quality studies, while following systematic stages for the review.

2.3.1 Eligibility criteria

This review followed strict eligibility criteria to ensure a more focused literature review. The inclusion and exclusion criteria are summarised in Table 2.1. The criteria involved including studies on CYP aged 0-18 years old from

both genders, who had been diagnosed with CHD including various CHD severities (mild, moderate or severe), and who had or had not experienced surgical or non-surgical interventional procedures. The studies may or may not include parents' proxy reports. Any study which included children who were older than 18 years old, and were diagnosed with acquired heart disease, and complex anomalous or syndromes which involved CHD with other health conditions, such as down syndrome, were excluded from this review. Also, children with physical or mental, developmental, neurodevelopmental, cognitive, psychiatric, or psychological disorders or disabilities were excluded. These studies were excluded to avoid any possibility of the findings being confused by the influence of these disorders or disabilities on the children's behavioural and emotional status.

Moreover, any study that assessed or evaluated the behaviour and emotions of children with CHD as an outcome of their study, was included in this review. Studies which assessed other aspects besides the behaviour and emotions of children or the effect of any aspects of a child's life on their behaviour and emotions were excluded; for example, the effect of exercise on the behaviour and emotions of children, or studies that combined the evaluation of behaviour and emotions with neuro-developmental assessment, because these outcome measures are conflicted with the aim of this review in exploring only behaviour and emotions of CYP with CHD.

The initial version of the review, which was conducted in 2018, included a search for studies published between the periods January 2000 and December 2017. The search was started from the year 2000 to ensure that this review comprises recent published studies about the behaviour and emotions in CYP with CHD. Any published papers before 2000 were excluded from the review. Then, the search was updated in October 2021 to include papers published between January 2018 and October 2021. More description about the updated search in 2021 will be provided next in this Chapter.

Also, papers using languages other than English were excluded because translating them into English for the purpose of this review was outside the scope of this study. However, English language studies conducted in any country and using any type of research methodology (qualitative, quantitative, and mixed methods), were eligible for inclusion.

Table 2. 1: Eligibility criteria for the literature review

Criteria	Inclusion criteria	Exclusion criteria
Population	-Male and female CYP (0-18 years old) -Diagnosed with CHD. All severities of CHD with or with no surgical interventions. -May involve parents' proxy reports.	- Participants older than 18 years old. - Children diagnosed with acquired heart disease, physical, developmental, cognitive, psychological disorders or disabilities. - Children with complex anomalous or syndromes involving CHD.
Outcome	The behavioural and emotional status of CYP with CHD.	-Measurement of the effect of other aspects besides the behaviour and emotions in CYP. -Measure of any other outcome besides the behaviour and emotions in CYP.
Methods	Qualitative, quantitative, and mixed methods studies.	__
Settings	Conducted in any country or setting	__
Publication years	Initial review search: from January 2000 to December 2017. Updated search: from January 2018 to October 2021.	Studies published before 2000 or after October 2021.
Publication language	English.	Any languages other than English.

2.3.2 Search strategy

A systematic search process was undertaken, starting by breaking down the review question into keywords and related terms using the Population, Exposure, Outcome (PEO) format. Then, dictionaries like Oxford and Merriam-Webster's were used to identify different synonyms for each keyword. Final keywords were selected with support from a librarian at the University of Leeds (Figure 2.1).

A comprehensive search of Medline, PsycINFO and CINAHL databases was undertaken to identify sources related to medicine, psychology, behavioural sciences, nursing and allied health professions. In the advanced search engine, the Boolean operators "and" or "or" were used to broaden the results. Adjacency of phrases was maintained by adding (adj) between the words, e.g. "Congenital adj heart adj disease". Moreover, using truncation (*, $) at the end of each keyword allowed retrieval of all possible results related to that word stem. These strategies enabled widening of the search results.

To update the earlier version of the review for the period between January 2018 and October 2021, the original search strategy, described above, was duplicated using the same databases. The results from the initial and updated searches will be explored next in this Chapter and summarised in a table (Appendix I).

Figure 2. 1: Planning search keywords and terms
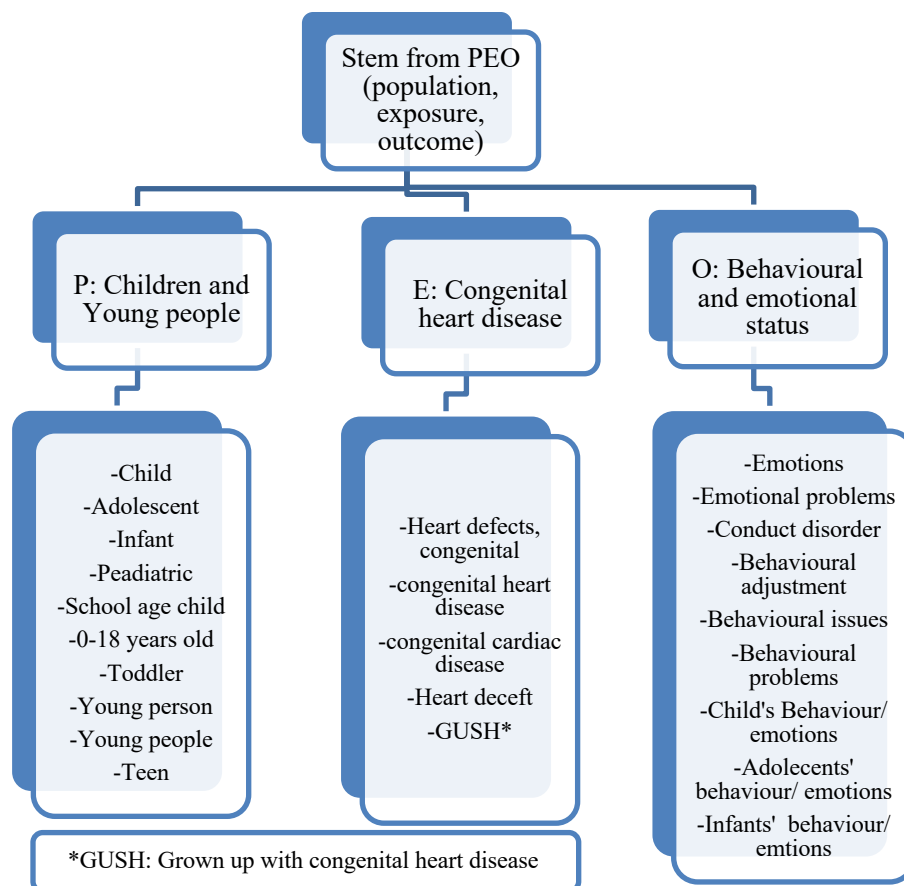
2.3.3 Study selection

The total number of articles retrieved from all three databases was (n= 2425). Covidence software was used to aid the screening of papers (Babineau, 2014) and importing them into Endnote reference manager to arrange and index references of all papers. Twenty duplicates were removed resulting in (n=2405); the remaining articles were screened by reading titles and abstracts, resulting in (n=96) studies. Then, the PhD supervisors reviewed (re-screened) the screened titles and abstracts of (n=96) studies. If the titles and abstracts were not clear, the full text was read by the researcher. The full text of (n=96) was assessed against the eligibility criteria (Table 2.1) by the researcher,

resulting in (n=8) included studies (Figure 2.2). Agreement was reached regarding the eligibility of the eight studies after discussing and checking with supervisors. The data of the eight studies were extracted into Table 2.2 and, the supervisors reviewed and agreed with the data extraction process. Then, quality appraisal of the eight studies was undertaken by the researcher, and the supervisors reviewed and agreed with the quality appraisal of two of the studies. Double-screening of the identified studies done by two independent coders is suggested by CRD (2009) as a way to improve the quality of the review and avoid mistakes that can occur if single-screening is done (Polanin et al., 2019). As this review was conducted as a part of the PhD study, double-checking was ensured by asking supervisors to review and double-check throughout the screening stages.

The updated search in October 2021 resulted in (n= 3046) of total articles retrieved from all databases. After removing 35 duplicates (n=3011), the remaining articles were screened by titles and abstracts. Only one study was found to be potentially eligible for inclusion in this review as indicated by its title (Jilek et al., 2021). However, by examining the full text against the eligibility criteria, it was found that the study measured predictive and associated factors to developing behavioural and emotional issues rather than assessing the behaviour and emotions of the children. Thus, according to the exclusion criteria of this review, this study was excluded from the review due to having an inappropriate outcome measure. A table describing the excluded studies with reasons for exclusion is presented in Appendix-II.

Figure 2. 2: PRISMA chart for studies selections
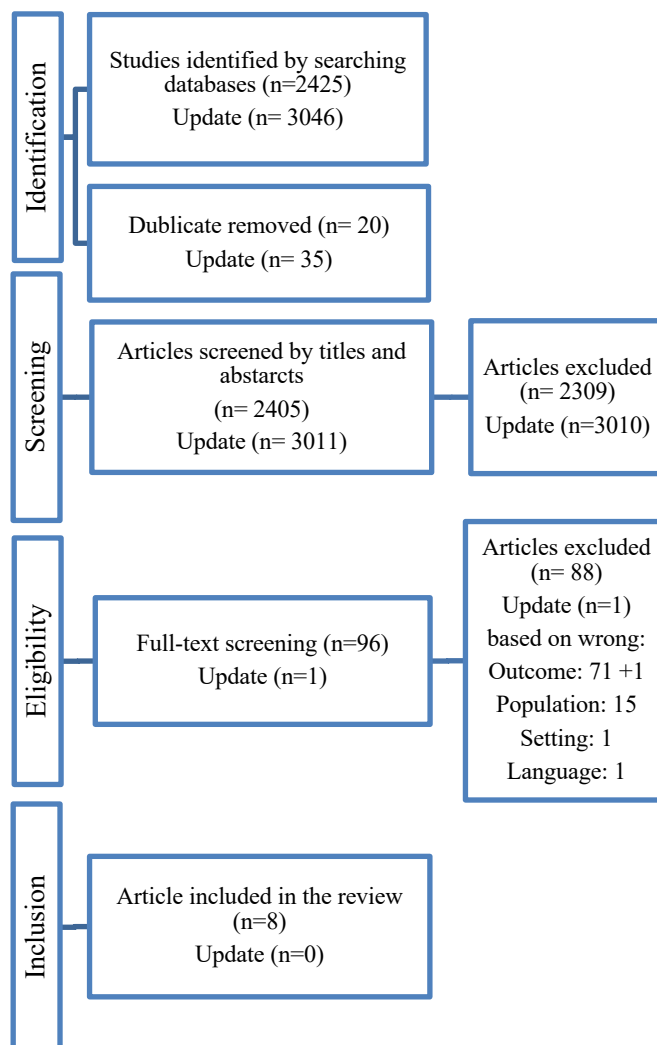
2.4 Data extraction

Following the CRD guidance on data extraction processes (CRD, 2009), information was extracted from the reviewed studies into a table, based on: general information (author name, year of publication, country of origin), study method, participants' characteristics, interventions, outcomes, and results (Table 2.2). All eight reviewed studies were quantitative in design. Case-control studies n=2 (Fredriksen et al., 2009; Guan et al., 2014), cohort studies n=3 (Miatton et al., 2007; Stene-Larsen et al., 2011; Stene-Larsen et al., 2010), and survey studies n=3 (Spijkerboer et al., 2008a; Spijkerboer et al.,

2008b; Yildiz et al., 2001). All studies were published in the English language and were conducted in the following countries: Belgium (Miatton et al., 2007), China (Guan et al., 2014), Norway (Fredriksen et al., 2009; Stene-Larsen et al., 2011; Stene-Larsen et al., 2010), the Netherlands (Spijkerboer et al., 2008a; Spijkerboer et al., 2008b), and Turkey (Yıldız et al., 2001). Only two studies included participants aged 6 to 36 months old (Stene-Larsen et al., 2011; Stene-Larsen et al., 2010), the others included 4-18-year-olds. Moreover, the studies varied in the methods of assessing behaviour and emotions in CYP with CHD. Some sought only parents' or mother's perceptions of their child's behaviours and emotions, using the child behavioural checklist (CBCL), (Guan et al., 2014; Yıldız et al., 2001), Infant Toddler Social and Emotional Assessment (ITSEA) (Stene-Larsen et al., 2011), or Infant's Characteristics Questionnaires (ICQ) (Stene-Larsen et al., 2010). On the other hand, others combined parents' perceptions using the CBCL with CYP's self-perceptions using the Youth Self Report (YSR) (Fredriksen et al., 2009; Miatton et al., 2007; Spijkerboer et al., 2008a; Spijkerboer et al., 2008b). Validity and reliability of the questionnaires and checklists used in the reviewed studies were assessed and confirmed in different settings and populations (Frizzo et al., 2015; Geibel et al., 2016; Liang et al., 2020).

2.5 Quality appraisal of included studies

All studies were critically appraised using the Mixed Methods Appraisal Tool (MMAT), a standard appraisal tool with confirmed reliability and validity of its pilot version (Pace et al., 2012; Pluye, 2011) (Appendix-III). The reliability and validity of MMAT were also demonstrated in this review. Scoring of a paper's quality could be calculated as 25% if one criterion was met, and 100% if all criterion were met (Pluye, 2011). Moreover, most of the included studies did not specify a quantitative design. Therefore, MMAT was considered to be a suitable option as it

allows for assessing all quantitative studies using the same criteria. The researcher was able to customize the studies into randomized, non-randomized, and descriptive sections of the tool after reading and re-reading the full texts. Broadly, out of the eight reviewed studies, seven were rated as medium to high-quality (50% or 75%), and only one was rated as low-quality (25%). The high-quality study fulfilled almost all the quality criteria with clear descriptions and explanations. For the studies rated as lower quality, insufficient information was provided and led to difficulty in making an informed judgement about the research design. For example, the method was not mentioned, was not appropriate for the assessment made, or no adequate details were discussed. A study should describe what type of research design was followed to further identify whether the design is appropriate to answer the research question (Greenhalgh, 2019). The quality of each included study is presented in Table 2.2.

Selection bias, as one of the quality criteria in MMAT, can be introduced in case-control studies, which the researcher has to avoid by objectively deciding if an individual is a case, with an intervention, or a control, with no intervention, and to be sure that the allocation of the case and control groups are proportional and matched regarding demographic and health data (Greenhalgh, 2019). In this review, three papers (Guan et al., 2014; Miatton et al., 2007; Spijkerboer et al., 2008b) have avoided selection bias by providing a clear description of populations with the inclusion and exclusion criteria of both groups to ensure the accuracy of the sample frame (Delgado-Rodriguez and Llorca, 2004). Moreover, follow-up rate and complete outcome data were provided in five papers (Fredriksen et al., 2009; Spijkerboer et al., 2008a; Spijkerboer et al., 2008b; Stene-Larsen et al., 2010; Stene-Larsen et al., 2011). The two other papers did not report on data completion which is considered as a lower-graded level of quality according to MMAT. Failure to report the duration of the follow-up can mislead the reader in identifying if the assessment or the intervention has been available for a

sufficient period of time so that the results were saved from being biased (Greenhalgh, 2019). In the study by Yıldız et al. (2001), the only descriptive study and low quality (25%) study in this review, the sample strategy and measurements used were clear and relevant to the research aim. However, no conclusion could be reached on the representativeness of the sample as no inclusion and exclusion criteria were reported, and no reasons for participants' exclusion were explained which suggests the occurrence of selection bias. Also, the response rate or completion of outcome data were omitted from the reporting of this study.

From all eight studies, only five studies clearly justified and defined the measurements and variables, and the validity of the measurements was demonstrated (Guan et al., 2014; Miatton et al., 2007; Spijkerboer et al., 2008a; Stene-Larsen et al., 2011; Stene-Larsen et al., 2010).

Table 2. 2: Characteristics of the reviewed papers

Title	Study	Country/ Method	Participants	Interventions / outcome measures	Outcome	Follow up / response rate	Results	Quality rating
1) Children and adolescents with congenital heart disease: assessment of behavioural and emotional problems	Fredriksen et al., 2009	Norway - No method type was stated: case-control study	-Children and adolescents with CHD aged 11- 16-year olds and their parents (n=430) - Healthy children in control group (n=368)	Using questionnaires: -Youth self-report (YSR) by children of 11-16 year old in both groups (child self-report) - Child behavioural checklist (CBCL or CBC) by parents of children in both groups (parents' proxy reports)	Behavioural and emotional problems	Response rate of 71.4%	-Children with CHD reported lower problems than the control group. - Children with CHD, by self-report, reported themselves with greater problems than their parents reported them. -Boys with CHD showed more somatic problems compared to girls in the same group.	75%
2) Behavioural and emotional outcomes in school-aged children after surgery or transcatheter closure treatment for ventricular septal defect	Guan et al, 2014	China -No method type was stated: Case control study	-Total of 64 school age children aged 6-13-years old with ventricular septal defect (VSD): children post-surgery (n=29), and post-trans-catheter closure (n=35). -Healthy children of control group (n=56). -Their parents: mothers (n=79), fathers (n=41).	Using questionnaires: -CBC: by parents of children in all groups (parents proxy reports) -General health questionnaire: to evaluate parents' psychological status. - Intelligence quotient test (Wechsler Scale for children-second edition): completed by only 34 children from all groups.	Behavioural and emotional problems	No response rate was reported	-Children with CHD who were post-surgery and post-trans-catheter showed more internalizing behavioural problems than controls. Mainly somatic complaints, depression, social withdrawal. -Post-surgery boys exhibited greater depression and somatic complaints than post-trans-catheter closure boys and healthy boys.	50%

Title	Study	Country/ Method	Participants	Interventions / outcome measures	Outcome	Follow up / response rate	Results	Quality rating
3) Behavior and self-perception in children with a surgically corrected congenital heart disease	Miatton rt al., 2007	Belgium - No method type was stated: follow-up cohort study	- On parents' proxy report: children with surgically corrected CHD aged 6- 12- years old (n=43). Matched age and gender of healthy children control group (n=43). -On children's self-report: children with CHD who are 8 years and older(n=23) . matched age and gender healthy children control group (n=23).	-Parents' proxy reports: using CBC -Children self- report for 8 years and older: using self-perception profile for children scale, children's depression inventory, and state trait anxiety inventory.	Behavioural outcomes and self-perception of children	No follow up or response rate were reported	-Parents of children with CHD reported higher school problems, and higher aggressive, social and attention problems than the parents of control group -Children on self-report showed no significant difference between children with CHD and the control	75%
4) A historical comparison of long-term behavioral and emotional outcomes in children and adolescents after invasive treatment	Spijkerboer et al., 2008b	The Netherlands - No method type was stated: follow up study (Survey)	-Recent sample: children with CHD and post cardiac surgeries aged 10-17- years old (n=84) -Their parents (n=90) -Historical sample: children with CHD who had their	- Using CBC: parents' proxy reports of children aged 11-17-year olds -Using YSR: children's self-report aged 11 -17 years old	Behavior and emotional outcome	-Response rate of children for YSR: 73% -Response rate of parents for CBC: 75%	No significant difference between the recent and historical samples in behavioural and emotional problems. -Parents of children with CHD reported their children with more behavioural problems in both recent and historical samples.	50%

Title	Study	Country/ Method	Participants	Interventions / outcome measures	Outcome	Follow up / response rate	Results	Quality rating
for congenital heart disease			surgeries between 1968-1980				-Younger children aged 11-13-years old reported themselves with more withdrawal and depression problems than older children aged 14-17-years old.	
5) Long-term behavioural and emotional problems in four cardiac diagnostic groups of children and adolescents after invasive treatment for congenital heart disease	Spijkerboer et al., 2008a	The Netherlands -No method type was stated: Follow-up study (Survey)	-Children aged 11-17 years old with CHD and post invasive treatments (n=85) of four diagnostic groups: ASD,VSD,TGA,PS -Parents of children with CHD aged 7-17 years old (n=125).	- CBC: for parents' proxy reports -YSR: for children's self-reports	Behaviour and emotional problems	-At follow up, 46 parents refused to participate and 40 patients were lost -Response rate: 73%	-Parents reported higher level of emotional and behavioural problems, compared to the healthy children group. -Children themselves reported less behavioural problems than healthy children. -Boys scored with more behavioural problems than girls.	75%
6) Emotional reactivity in infants with congenital heart defects: findings from a large case-cohort study in Norway	Stene-Larsen et al., 2010	Norway - Longitudinal cohort study	-Infants with CHD (n=212) aged 6 months old and their mothers; assigned in two groups: Mild CHD: n=92 infants Moderate to severe CHD: n=120 infants	- Mothers' proxy report: using Infant Characteristics questionnaire (ICQ), fussy/difficult subscale.	Emotional reactivity	-Response rate 87% -19 infants were lost due to attrition	Infants with moderate to severe CHD have higher risk of emotional problems than infants with mild CHD	50%

Title	Study	Country/ Method	Participants	Interventions / outcome measures	Outcome	Follow up / response rate	Results	Quality rating
7) Longitudinal analysis of emotional problems in children with congenital heart defects: A follow-up from age 6 to 36 months	Stene-Larsen et al., 2011	Norway - Longitudinal cohort study	-Infants with CHD at age 6, 18, 36 months old (n=175) and their mothers -Control group	- Mothers' proxy reports using CBC, and 12 selected items from the Infant Toddler Social and Emotional Assessment (ITSEA)	-Emotional and behavioural problems	-Response rate 62%	Children at 36 months old with all severity of CHD did not show high risk for internalizing or externalizing problems at age 36 months compared to control group	50%
8) Evaluation of internal behaviors of children with congenital heart disease	Yıldız et al., 2001	Turkey -No method type was mentioned: Descriptive study	Children aged 4- 11 year olds with CHD and their mothers (n=96)	-Mothers' proxy reports using CBC: in a single 30-35 min interview. -21- item questionnaire to obtain mothers-child information.	Internal behaviour	No response rate was reported	-Internal behavioural problems were demonstrated in all sampled children - Children with worse cardiac conditions show higher level of behavioural problems.	25%

2.6 Review results

The findings are presented below as a narrative within three categories:

2.6.1 Identified behavioural and emotional issues in CYP with CHD

This category presents results from the reviewed studies about the common behavioural and emotional issues in CYP with CHD. Children's perceptions and parents' proxy reports about the children's behaviour and emotions and agreement between both reports are also presented in this section.

All reviewed studies indicated the presence of behavioural and emotional problems/ issues in CYP with CHD. Perceptions were only attained from parents in half of the studies (n= 4; proxy reports), whereas other studies combined parental proxy reports and CYP self-perceptions (n= 4). In studies that obtained only parents' proxy reports about their CYP's emotional and behavioural problems, parents reported internalizing behavioural problems in school-aged children (6–13 years) with ventricular septal defects (VSDs) in China (Guan et al., 2014) and children (aged 4–11 years) with different severities of CHD in Turkey (Yıldız et al., 2001). Two other studies, in Norway, focused on mothers' perceptions only, and showed that infants' demonstration of different emotional problems depended on their age and CHD severity (Stene-Larsen et al., 2011; Stene-Larsen et al., 2010). From the above results of reviewed studies, it was noted that even though there were differences in culture, child age, and CHD severity in CYP, all parents were alike in reporting the existence of behavioural and emotional problems in their CYP such as internalising, externalising, depression, and social withdrawal.

When the reviewed studies combined parents' and CYP's perceptions, disagreements were noticed between the perceptions of both groups. Parents

reported their CYP (using the CBCL) (Achenbach, 2001), with higher scores of behavioural and emotional problems than their CYP perceived themselves using the self-perception profile for children (Harter, 1985), and the State Trait Anxiety Inventory for children (Miatton et al., 2007; Spielberger, 1983). In other studies, CYP perceived themselves with more behavioural, internalizing and externalizing problems (Fredriksen et al., 2009), with higher total scores of social withdrawal, depression, attention and behavioural and emotional problems than their parents reported them to be (Spijkerboer et al., 2008a).

Proxy reports of parents of CYP with CHD vary from the proxy reports of parents of healthy CYP. Parents of CYP with CHD rated their CYP with more problems than parents of healthy CYP in terms of somatic complaints, social problems, attention problems, internalizing problems, and in the total scores of behavioural and emotional problems (Spijkerboer et al., 2008a), a higher level of behavioural, attention, and aggressive problems (Miatton et al., 2007) and greater internalizing behavioural problems (Guan et al., 2014). These findings indicate that CYP with CHD demonstrated greater behavioural and emotional issues than healthy CYP did, which indicates the importance of future research to further investigate and understand how and why CYP with CHD develop behavioural and emotional issues, thus improving care and early assessment of behaviour and emotion of CYP with CHD.

Contradictory reports arose when CYP were asked to report their own views. The self-perceptions of CYP with CHD in comparison to the self-perceptions of healthy CYP were investigated in only four studies (Fredriksen et al., 2009; Miatton et al., 2007; Spijkerboer et al., 2008a; Spijkerboer et al., 2008b). Unlike in the proxy reports of parents, CYP with CHD reported themselves with either lower levels of behavioural and emotional issues (Fredriksen et al., 2009; Spijkerboer et al., 2008a), or with no higher scores than healthy CYP (Miatton et al., 2007). Comparison was also made between historical and recent samples of CYP with CHD by Spijkerboer et al. (2008b), where the

recent sample included those who had their operations or cardiac catheterizations between 1990 and 1996, and the historical sample of those who had their operations between 1968 and 1980. Although in the recent sample more advanced medical and surgical procedures and techniques were used for CHD than were used in the historical sample, CYP were still developing behavioural problems (Spijkerboer et al., 2008b). Parents of CYP with CHD in the recent and historical samples reported that their CYP exhibited similar levels of behavioural problems, and with more behavioural problems than healthy CYP (Spijkerboer et al., 2008b). Furthermore, parents' reports and CYP's self-reports did not differ in this study, as both reports demonstrated behavioural and emotional problems in CYP with CHD in recent and historical samples (Spijkerboer et al., 2008b). However, the study lacked explanations of reasons for these similarities in recent and historical samples. This highlights the need to investigate other factors contributing to CYP's behavioural and emotional issues.

From the reviewed studies, it was identified that CYP with CHD demonstrated more behavioural and emotional issues such as internalising and externalising behavioural issues, social withdrawal, aggressive and attention problems, and greater scores of behavioural and emotional problems than healthy CYP. However, some of the reviewed studies identified dissimilarity between the perceptions of parents and children, indicating that children perceive themselves differently from their parents. Indeed, CYP perceive themselves with more, similar, or less levels of behavioural and emotional issues than their healthy peers, compared to the reports of their parents. Moreover, parents of CYP with CHD scored their children with greater behavioural and emotional problems than parents of healthy CYP scored their children.

2.6.2 Relationships between age and gender and the behavioural and emotional issues in CYP with CHD

This review found that age and gender of children were related to developing behavioural and emotional issues, as identified from some of the reviewed studies. The results from the reviewed studies concerning the age and gender of CYP with CHD impacting their behavioural and emotional issues are discussed under this category.

It was found that gender had influenced the behaviour and emotions of CYP with CHD. Boys were reported to have scored themselves with more somatic complaints than girls (Guan et al., 2014; Spijkerboer et al., 2008a), and with more total behavioural problem scores in CBCL (Fredriksen et al., 2009). Somatic complaints is a psychological term referring to symptoms such as pain and fatigue, which might be associated with medical conditions (e.g. heart disorder, or cancer), or might be of unknown cause (Henningsen, 2019). These findings suggested that boys with CHD develop more behavioural problems than girls with CHD. This conclusion indicates the need for further research to explore the reason for differences in the demonstration of behavioural and emotional issues between boys and girls.

Age and behavioural problems were not related among young children (4–11 years) in the study by Yıldız et al. (2001). However, in Spijkerboer et al. (2008a), younger children (aged 11–12 years), in comparison to older children (aged 13–17 years), perceived themselves with more anxiousness/depression, rule-breaking, aggressive behaviour, externalisation problems, somatic complaints, and higher total behavioural problem scores. Other reviewed studies also revealed behavioural problems in young children of 6–12 years (Miatton et al., 2007) and 6-13 years (Guan et al., 2014).Thus, younger children were found to have more behavioural and emotional problems. Relying on these findings, it was anticipated that younger children's behaviour and emotions could be affected by the time of the first invasive treatment for

CHD that the child received. A prediction might be that the younger the child's age at the time of their invasive treatments the more behavioural and emotional problems they may display. This was demonstrated by Guan et al. (2014) who found that age at invasive treatment is a risk of behavioural problems for 6- to 13-year-olds with CHD. However, the influence of age at invasive treatment on the development of behavioural and emotional problems was not demonstrated in the studies of Spijkerboer et al. (2008a), or Miatton et al. (2007).

Nevertheless, conflicting results were demonstrated in the two studies which included infants (Stene-Larsen et al., 2011; Stene-Larsen et al., 2010). In a longitudinal study investigating the risk of developing emotional problems in infants with CHD, mothers of the infants reported that at age 36 months, their infants showed no risk for developing, internalizing or externalizing emotional problems (Stene-Larsen et al., 2011). The same infant group, that is the subgroup with moderate to severe CHD, at an earlier assessment when they were six months old, showed 60% higher risk of developing emotional problems (Stene-Larsen et al., 2011; Stene-Larsen et al., 2010). It was also acknowledged in the same study that the results may have been affected because they have selected items from two different tools (CBCL, and ITSEA checklists) were used for the infants' assessments (Stene-Larsen et al., 2011). Although these were the only two studies in this review which assessed infants' emotional status (Stene-Larsen et al., 2011; Stene-Larsen et al., 2010), the results of no emotional problems being found among 36 month-olds were explained as infants demonstrating no or having few emotional problems (Karsdorp et al., 2007; Stene-Larsen et al., 2011).

Age and gender were found to be related to the development of behavioural and emotional problems in CYP with CHD. In particular, boys, compared to girls, develop more behavioural issues. Moreover the reviewed studies revealed that young children are more prone to developing behavioural and

emotional issues than older children, which highlights the need for investigating younger children's behaviour and emotions.

2.6.3   Children developing behavioural and emotional issues related to the CHD complexity and treatment severity

Different CHD complexities can lead to different kinds of treatments or management, which could be through medications (non-invasive treatments) or cardiac-catheter or cardiac surgery (invasive treatments) (NHS, 2021). When investigating the relation of the presence of behavioural and emotional issues in CYP with CHD and the different invasive treatments they had undergone, three studies revealed different conclusions.

In comparisons between the cardiac-catheter and cardiac-surgical treatments, boys, in Guan et al. (2014) study who were post-heart surgery, exhibited more significant depression and somatic complaints compared to boys of post-cardiac-catheter interventions and healthy control boys, whereas girls who were post-heart surgery showed more negative thoughts, depression, somatic complaints and social withdrawal problems than healthy girl controls (Guan et al., 2014). Additionally, CYP who had undergone both invasive treatments exhibited more behavioural problems than healthy CYP, and more behavioural problems were found among CYP in the post-surgical group than the post-catheter group (Guan et al., 2014). These findings reveal that even though boys exhibited more behavioural problems than girls who demonstrated more social, depression and thought problems, they both had a high incidence of behavioural and emotional issues when they had undergone heart surgery compared to healthy boys and girls or those who had undergone cardiac catheterisation (a less invasive treatment).

When Spijkerboer et al. (2008a) compared four CHD diagnostic groups of different CHD severities, they found that CYP with VSD revealed more social and externalizing problems than CYP with atrial septal defect (ASD) and

pulmonary stenosis (PS), as reported by their parents. Medically, VSD comprises more severe symptoms than ASD and PS, which can explain the relationship between developing more behavioural and emotional issues in CYP with severe CHD. However, CYP's self-perceptions in the same study differed from parents' proxy reports. According to CYP's self-reports, no significant relationships were found between the severity of CHD and behavioural and emotional issues (Spijkerboer et al., 2008a). In contrast, in Turkey, it was found that the more severe the cardiac condition, the higher the withdrawal behaviour and somatic complaints that were demonstrated in CYP with CHD (Yıldız et al., 2001). The study proposed an explanation of the greater behavioural issues in CYP with severe CHD, as it can relate to family's and mothers' influence on their children (Yıldız et al., 2001), and the more educated the mothers the less behavioural and emotional issues were reported in CYP with CHD (Jackson et al., 2016). In a study of infants aged 36 months with different severities and diverse invasive treatments of CHD, all infants did not differ in showing any risks of developing emotional problems (Stene-Larsen et al., 2011). However, when they were six months old with moderate-severe CHD, they did demonstrate 60% higher risk of emotional problems (Stene-Larsen et al., 2010). Further research on infants could contribute to enhance understanding of their behavioural and emotional status.

Despite the intention of Spijkerboer et al. (2008b) to include CYP with different severities of CHD who had undergone invasive treatments, the effect of the type of invasive treatments on CYP's behaviour or emotions was reported as unknown (Spijkerboer et al., 2008b). Likewise, due to the small sample (n= 43) of CYP with mild severity of CHD (Miatton et al., 2007), no conclusion could be drawn about the effect of CHD severities on CYP's behaviour and emotions, as acknowledged by Miatton et al. (2007). Also, in studies of CYP with different severities of CHD, but with no report of the type of treatments of CHD (invasive or non-invasive), no differences in

behavioural and emotional problems were found across all severities of CHD in Norway (Fredriksen et al., 2009).

Although some reviewed studies demonstrated that more invasive treatments of CHD (e.g. heart surgery), and severe types of CHD (e.g. VSD) contribute to greater behavioural and emotional issues in CYP, other reviewed studies did not reach similar conclusions, either because of the small sample size, or because the relationship was not investigated. However, when CYP provided their self-perceptions, conflicted reports were provided across the studies. Some of CYP's self-perceptions showed no link between their CHD severities and their behavioural and emotional issues; while others' self-perceptions indicated higher rates of behavioural and emotional issues when they had severe CHD. There is scope for exploring the inconsistency in CYP's self-perceptions in future research, as it can speculated that other factors could contribute to some CYP viewing themselves with less problems while others with more problems.

2.7   Synthesis of the reviewed literature

This review identified the common behavioural and emotional issues in CYP with CHD through the parents' proxy reports and CYP's self-perceptions, and a disparity was noted between child and parents' perceptions. CYP, in some reviewed studies, perceived that they experienced more issues than as assessed by their parents. This, as justified by some of the reviewed studies which included parents' proxy reports, could have been related to disparities between parents and CYP in terms of their recognition of children's behavioural and emotional issues, or the parents' denial of their CYP's illness (Fredriksen et al., 2009). On the other hand, other parents may have overestimated their child's level of behavioural and emotional issues. Miatton et al. (2007) speculated that parents of CYP with CHD might be worried about their child's condition, or be more attentive to the related issues of their children's illness (Spijkerboer et al., 2008a), and therefore tend to over-estimate the presence of

issues in their children (Miatton et al., 2007; Spijkerboer et al., 2008a). Nevertheless, parents of children with chronic-illnesses in Nabors et al. (2019) were found to be the main source of support for their children throughout their illness journey by providing emotional support, staying close to the children, and administering medications.

Other CYP perceived themselves to have fewer behavioural and emotional issues than their parents did, which can be justified as they could fail to admit the presence of problems and try to live as normal a life as possible. This was discussed in one of the reviewed studies, as patients sometimes refuse to be recognised as patients or deny the existence of the disease, which may lead them to deny the existence of behavioural and emotional problems (Fredriksen et al., 2009). Hence, this could lead to them not seeking medical advice or care when needed, especially with older children when, sometimes, their parents become less involved in taking care of them.
However, ombining both perceptions of parents and CYP was important for a comprehensive understanding of the behaviour and emotions of CYP with CHD, as acknowledged by the authors of two studies included in this review (Fredriksen et al., 2009; Spijkerboer et al., 2008a).

It is also important to highlight that no qualitative studies and only quantitative studies were found in the international literature concerning the assessment of the behavioural and emotional status of CYP with CHD. Therefore, in-depth exploration of CYP's self-perceptions and parents' proxy reports on the behavioural and emotional status of CYP with CHD was limited. Deeper exploration is needed in addressing situations such as the disparities between parents' and children's perceptions, or the link between heart surgery and behavioural and emotional issues. A more in-depth investigation can best be achieved by using a qualitative design, as it needs an exploratory approach that aims to look at CYP's perceptions in depth (Pope and Mays, 2020).

Few studies in this review have investigated the effect of age and gender on behavioural and emotional status in CYP with CHD. Understanding the differences, if present, between boys and girls in developing behavioural and emotional problems will facilitate the development of individualised interventions to reduce these problems. Hence, child age and different developmental stages for each child regardless of chronological age could also impact the presence of behavioural and emotional problems. Therefore, if young children develop more problems than older children, as demonstrated in Spijkerboer et al. (2008a), then different supportive interventions should be delivered to the younger age group. However, further investigations should be conducted around the influence of the child's age, developmental stage, and gender on the behavioural and emotional status of CYP with CHD.

It is noteworthy through the literature review that the views of children under seven years old regarding their own behaviour and emotions was unknown. Instead, parents' proxy reports were attained. As this review revealed that younger children had more behavioural and emotional issues than older children, according to their parents' proxy reports, it is crucial to investigate further, younger children's self-perceptions about their behaviour and emotions. Moreover, it can be predicted that children under seven years of age may have different views about their behaviour and emotions than parents perceived in the reviewed studies, since children older than seven year of age had contradicted the perceptions of their parents. Thus, a better understanding of the behaviour and emotions would be achieved by gaining the children's personal perceptions and hearing their voices. Furthermore, it is the right of children to be heard and to provide their perceptions of something concerning them, as reported by the United Nations Convention on the Rights of the Child UNCR (1989). However, it is not possible to ask for the self-perceptions of infants until they reach the age of two or three years. The age range of 2 to 7 years old is wide and it requires a specific research methodology which is suitable for children's developmental stages (O'Reilly and Dogra, 2016). The

dearth of evidence in the younger age range led to the inclusion of 4-10 year olds in this study, with methodological and ethical considerations suitable to this age group. Further descriptions of research methods and methodology are presented in the following chapters.

Moreover, the reviewed studies demonstrated that CHD complexity and disease severity seemed to have a consistent effect on the behaviour and emotions of CYP with CHD. The higher the complexity of CHD, the worse the behavioural and emotional status of CYP with CHD, which can be explained by prolonged hospitalisation for children who have undergone heart surgery as a management for their moderate to severe conditions. Long durations of hospitalisation periods for CYP related to complex conditions (e.g. cancer), were found to influence the psychosocial issues in CYP (Obaid, 2015). Another explanation could be that the development of emotional problems in CYP with moderate to severe CHD is related to the genetic link between the heart and the child's behaviours and emotions, especially after the heart surgery (Walker et al., 2012). Likewise, the more invasive the management procedures, the greater the behavioural and emotional issues. Post-surgical CYP presented more behavioural and emotional issues than post-cardiac-catheter CYP. These findings indicate the significance of having an in-depth understanding of the development of behavioural and emotional issues among CYP with severe CHD and surgical treatments, which can lead to the identification of preventative measures such as adequate pre-operative preparation, and the provision of psychosocial support.

The significance of conducting this study in Saudi Arabia was highlighted by the need to understand children's behaviour and emotions, as described earlier (see Chapter 1). Moreover, there is a need for practical interventions supporting the behavioural and emotional status of children with CHD in SA, as there is a high incidence rate of CHD found in SA, and no standardised psychosocial support programs have been identified for families of children

with CHD in SA. However, due to a lack of knowledge found in SA about the behaviour and emotion of children with CHD (Almesned et al., 2013), future research is needed to provide an initial understanding based on both children's and parents' perceptions. Therefore, conducting research using an inductive approach based on values and meanings of individuals (Charmaz, 2014), which in this study are children and parents, and subsequently generating a theory can aid the attainment of basic knowledge about CHD and children's behaviour and emotions in SA.

2.8 Summary:

This chapter presented a literature review which included studies from 2000-2021 of children with CHD and was related to their behaviour and emotions. Parents' proxy reports were involved in all of the reviewed studies, but only some of the reviewed studies explored the self-perceptions of CYP, which were obtained only from children aged seven years and older. Indeed, it was highlighted in the reviewed studies that future research ought to consider CYP's perceptions about their own behaviour and emotion rather than relying only on parents' proxy reports. However, it is vital to incorporate parents' proxy reports (parents' perceptions) along with their CYP's self-perceptions to gain a more holistic understanding of children's behaviour and emotions.

It was identified that there is a need for future qualitative studies that explore in-depth the self-perceptions of CYP with CHD regarding their behaviour and emotions, especially for those who are younger than seven years old. There is an international gap in qualitative research on this topic among young children with CHD. For the purpose of this study, addressing this gap was a stimulus for this study to be the first that qualitatively explores behaviour and emotions of children with CHD in Saudi Arabia.

This review also reveals that CYP with CHD develop behavioural and emotional issues. CYP with severe CHD and who have undergone heart surgery demonstrated greater behavioural and emotional problems than CYP with less severe CHD and who have undergone less invasive treatment procedures. Moreover, disparities between perceptions of parents and children about the children's behaviour and emotions were clearly demonstrated. Further justifications or explanations of the differences between the two perceptions are needed. Also, future research can focus on the relationship between gender and the behavioural and emotional issues in CYP with CHD.

The updated search for this review was undertaken for the period between January 2018 and October 2021. No additional studies were found to be eligible for inclusion in this review, which can confirm the continuation of a research gap since the initial literature review and the need to research behaviour and emotions of children with CHD. Also, it confirms the significance for conducting the current study in SA. This study was conducted using Grounded Theory (GT) methodology following Charmaz's approach (Charmaz, 2014). Thus, this literature review was conducted in accordance with Charmaz's guidance for a research thesis to include a chapter for a literature review. Moreover, Charmaz's constructivist philosophy indicates that reviewing literature prior to or during the GT study can help reveal research gaps and enhance understanding of the researched context (Charmaz, 2014; Kenny and Fourie, 2014), which was evident from the results of this literature review. The next chapter provides further justification for choosing GT as a methodology for this study, and describes the philosophical assumptions of the GT methodology.

Chapter 3 Research Methodology

3.1 Introduction

This chapter discusses the rationale for choosing a qualitative approach and selecting a Grounded Theory (GT) methodology. This chapter also presents the history and philosophical views of GT, different approaches to GT and the selection of Charmaz's approach to GT (Charmaz, 2014). Moreover, this chapter provides a descriptive overview of the key processes or stages in GT.

3.2 Research aim and objectives

The research question was informed by the literature review (Dahlawi et al., 2020) which was undertaken as a part of this PhD study:

"What are the perceptions of 4-10-year-olds with CHD in Saudi Arabia, and their parents' proxy reports about children's behaviour and emotions?"

Because of the lack of qualitative research in this area, as confirmed by evidence reported in Chapter 2, the aim of this research was to explore the perceptions of children aged 4-10-years old with CHD in Saudi Arabia (SA), and their parents' proxy reports, about the children's behaviour and emotions.

The objectives were as follows:

- To explore the children's accounts of their behaviour and emotions

- To investigate the parents' proxy reports, about their children's behaviour and emotions

- To develop a theory that aids understanding about the behaviour and emotions of children with CHD

3.3 Qualitative research

Qualitative research was defined by Denzin and Lincoln (2011) as studying things and phenomena in their natural settings and interpreting their meanings, as provided by people through interviews, field notes, or photographs. A description of how to conduct qualitative research was provided by Creswell and Poth (2018), which begins with a philosophical assumption regarding the study of an identified research problem in humans, and involves individuals or social contexts. Then, according to which qualitative research approach is selected, data will be collected from the natural places where the problem was identified and analysed through establishing themes or patterns from the data (Creswell and Poth, 2018).

Initially, to examine the suitability of using qualitative research in this study, the aim and objectives were revisited, and the utilisation of qualitative research was explored. Qualitative research is most relevant in situations where there is a need for in-depth understanding of a phenomenon that was, for example, identified and reported in previous quantitative research, and then exploring the context from where the identified problem or issue arises, and/or providing opportunities for unheard voices and stories to be retrieved (Creswell and Poth, 2018). Accordingly, the researcher found qualitative research most appropriate for this study. First, this was because the aim was to explore in depth the unheard children's voices and their parents' proxy reports about something concerning the children (a phenomenon). Second, there was a desire to address the lack of published qualitative research on the behaviour and emotions of children with CHD, as reported in the recent literature review (Dahlawi et al., 2020).

Another reason for selecting qualitative research was related to its unique characteristics, one of which is the potential it offers for studying a phenomenon related to a particular group of people in a specific culture or society (Tracy, 2019). Also, in order to study a problem specific to a certain

group of people, it is vital to collect data from their natural settings, which is another characteristic of qualitative research. Furthermore, qualitative research is characterised by the complexity, richness and depth of data to help understand the meanings and interrelations of a phenomenon (Flick, 2018). By evaluating these characteristics, it was confirmed that a qualitative research approach was suitable for this study as it was intended to obtain accounts from a specific group, who are children with CHD in SA. Moreover, the researcher was aiming to attain rich data that deeply explored the behaviour and emotions of the children, which is one of the characteristics of qualitative research.

Qualitative research is broadly used in a variety of disciplines through many different qualitative approaches, though five approaches, namely narrative research, phenomenology, Grounded Theory, ethnography, and case study, were identified as most commonly used in the social and health sciences by Creswell and Poth (2018). Deciding between the five approaches of qualitative study is typically based on the research focus and problem. The research focus is about the broad idea of the research or the aim and objectives of the study, which is driven by a more precise research problem (Creswell and Poth, 2018). To select the most suitable qualitative approach for this study, all five approaches were examined against the focus and problem of this research.

Narrative research is about exploring stories of individual lives in a specific setting and the social, cultural, and contextual aspects in which these individuals experienced their narrated stories. Their stories and personal experiences are gathered to make meanings of their experiences and honour their lived experiences (Clandinin, 2016). From the definition above, it was recognised that narrative research was not an appropriate approach since this study aimed to obtain views of children and parents on something specific to the children with CHD (their behaviour and emotions), and not the general stories of their experiences. Phenomenology was also not appropriate as it is a study of a certain phenomenon through people's lived experiences and

perceptions of the phenomenon (Flood, 2010). On the other hand, this study sought to understand particular behaviours and emotions and the complex links of CHD with the behaviour and emotions in children rather than studying the children's experiences of having CHD more broadly.

Ethnographic research is designed to study cultural and shared beliefs or views of people who usually interact together in the same place such as a group of teachers at a school (Creswell and Poth, 2018). Thus, ethnography was not appropriate as this study did not intend to explore mutual perceptions of children's behaviour and emotions. Moreover, using observation, which is usually involved in ethnography, was found unfeasible, as it was not possible to immerse in the daily lives of children to observe their behaviour and emotions. Furthermore, because this study's focus was not to study an event or activity of one or more individuals (single or multiple cases) within a specific setting, case study research was also found to be not suitable (Yin, 2018).

The primary reason for choosing GT was determined by the literature gap found in the researched area, as there is little known from young children's perspectives and their parents in previous literature about children's behavioural and emotional status as they live with CHD in SA. Therefore, it was essential to inductively explore the relationships between CHD and children's behaviour and emotion and generate a theory grounded on children's and parents' perceptions, as identified in Chapter 2. Thus, by reviewing the research focus and problem, the researcher was able to identify that GT was most appropriate for this study. The research focus of this study was to develop a theory about the behaviour and emotions of children with CHD. In addition, Table 3.1 summarizes the five qualitative approaches.

Table 3. 1: Options of qualitative research approaches

Qualitative research approaches	Focus of the research approach
Narrative research	Understanding meanings of narrative stories of individuals' lives within a specific context (Clandinin, 2016).
Phenomenology	Exploring people's lived experiences of certain phenomena, and how they perceive the phenomena (Flood, 2010).
Ethnography	Studying the common cultural beliefs of a group of people who live or work together in the same place (Creswell and Poth, 2018).
Case study	Exploring single or multiple views of individuals to understand an issue within a specific setting or environment (Yin, 2018).
Grounded Theory	Inductively developing a theory from grounded data following a set of systematic methods and procedures (Charmaz, 2014).

3.4   Grounded Theory method

As described above, GT is a qualitative approach that aids in developing a theory generated from grounded data. GT is an iterative and systematic process, in which the researcher starts inductively from the data to identify emerging conceptual concepts and eventually a theory, by constantly going back and forth between the collected data and the emergent themes or codes (Charmaz, 2014; Charmaz, 2017). GT allows the provision of perceptions and an explanation of behaviours, as it is drawn from a sociological background (Charmaz, 2014; Glaser and Strauss, 2017; Glasser, 1999). Many qualitative researchers in different fields have welcomed the use of GT because of its

flexibility and feasibility with various types of data (Walsh et al., 2015). Through GT, the researchers can generate new concepts and relationships between new and existing knowledge, which might be undiscovered previously, therefore adding to the researched field's literature, which, in the current study, is the relationships between children's behaviour and emotions and their CHD (Martin et al., 2018).

Theoretical pacing is a unique feature in the process of conducting GT, in which many stages of research are done at the same time to develop a theory (Gibson and Hartman, 2013). According to Glaser and Strauss (1967), developing a GT depends on the constant comparative method. It includes comparing incidents to emergent categories, integration between the categories and their properties, theory formalization, and writing the theory (Glaser and Strauss, 1967). Gibson and Hartman (2013) summarized the basic techniques of conducting a GT as sampling and theoretical sampling, data collection, coding the data including theoretical coding, reaching saturation, visiting the literature and comparisons with existing literature to support the theory development, sorting memos while developing categories of the emerged theory, and finally writing the theory. Further illustrations of the key process procedures of GT are provided later in this chapter.

GT provides guidelines for the research process and suggests tools for running successful research that can address a variety of problems regardless of the aim of developing a theory or not (Charmaz, 2017). Although the main aim of conducting GT is to develop a theory, not all researchers end up generating theory as some develop a model or categories that are grounded in the data (Bryant and Charmaz, 2007; Charmaz, 2014; Salsali et al., 2016). The generated theory can be substantive or formal, and to distinguish between these types of theories, Glaser and Strauss (1967) explained that substantive theory is particular to one substantive specific area with conceptualized categories that might be applied only to that specified area. In contrast, the

formal theory is broader, with more generalized categories and areas of applications. Nevertheless, theories resulting from GT are different from other existing theories, for example, in public health which is undertaken deductively and aims to enhance general population health. Theories from GT are developed inductively and grounded in the perspective of understanding a problem from the viewpoint of those who are affected by the problem (Gibson and Hartman, 2013).

3.4.1   History of Grounded Theory

Glaser and Strauss collaboratively published *The Discovery of Grounded Theory* in 1967. They were working together at the University of California, San Francisco and were distinguished as the first generation of Grounded Theorists. Since then, the popularity of using GT in developing a theory has been increasing among social scientists (Birks and Mills, 2015). In their book *The Discovery of Grounded Theory,* Glaser and Strauss (1967) introduced the fundamental principle of developing a theory from the data through constant comparative analysis, rather than testing existing theories. Furthermore, they adopted a philosophical assumption that reality is capable of exploration and can be discovered (Gibson and Hartman, 2013). Thus, the initial principles of GT, as identified by Glaser and Strauss, were identified as feasible for both quantitative and qualitative research and among a variety of philosophical assumptions such as positivism, interactionism, or constructivism, which enabled the spread of the use of GT in different fields (Walsh et al., 2015). However, through their book, Glaser and Strauss aimed to advance the application of qualitative research in particular and expand it to a more explorative, theoretical and conceptual approach of research (Charmaz, 2014). Together, Glaser and Strauss proposed that, in GT, data collection occurs in parallel with data analysis through the essential stages of theoretical sampling, coding, constant comparison, saturation and memo writing (Kenny and Fourie, 2014).

In the 1970s and 1980s, due to their conflicts in GT methodology, Glaser and Strauss split and progressed their published work in GT independently (Kenny and Fourie, 2014). However, a few years later, Straussian GT had been established from the original GT by Strauss and Corbin, who worked together on a book in 1990 (Strauss and Corbin, 1990). Consequently, Glaser critiqued the work of Strauss and Corbin and suggested that their book lacked principles; Glaser then published a book that defends the original GT, which was later recognised as the classic GT or Glaserian GT (Glaser, 1992). Soon, a third version was introduced to GT methodology by Kathy Charmaz, who was a doctoral student of Glaser and Strauss. In her GT version, she employed a more flexible GT methodology and followed a constructivist research paradigm (Charmaz, 2017; Kenny and Fourie, 2014). Further illustrations of the three versions of GT are discussed next.

3.4.2   Approaches of Grounded Theory

The three GT versions of Glaser, Strauss and Corbin, and Charmaz have similarities and differences, which can be confusing for the researcher who is aiming to choose the most suitable version as a research approach. Thus, it was essential to explore the aspects where the similarities and differences occur between the three approaches to select the most appropriate approach of GT for this study. The three approaches have different lenses through which they view the philosophical paradigm of GT, their ontology and epistemology (Singh and Estefan, 2018). Ontology is defined as having a position or perspective on the social world and the phenomenon being investigated. In contrast, epistemology is about what things count as knowledge and the evidence of the explored world (Mason, 2018). Hence, Glaser's GT believes in positivism and objectivism ontologies, which rely on one reality, and the researcher's perspective is left out to allow data to speak for itself (Glaser and Holton, 2004). On the other hand, Strauss and Corbin's views in their version of GT, are based on the post-positivism and objectivism ontologies which

understand that multiple views can exist. However, the researcher should remain objective (Strauss and Corbin, 1990).

Furthermore, Charmaz had a divergent philosophical assumption that relied on constructivism, allowing multiple views and realities, including the researcher's (Charmaz, 2014; Singh and Estefan, 2018). Charmaz (2014) argued that research is not just about observing the things as they are; thus, objectivists can only have a partial view or knowledge of the problem. Through her constructivism philosophical assumptions, she explained that realities or views are multiple, and that researchers' and participants' accounts are acknowledged. The researcher's input and interaction with data is part of the research product. Therefore, constructivists intend to integrate the data that emerges from participants with the researcher's interpretation of the phenomenon to give rise to a theory (Charmaz, 2014).

Another point where the three approaches differ is the researcher's focus or aim of conducting a GT. The focus in Glaserian GT is to develop a theory grounded only from the data and generalize it to a larger context. In comparison, Straussian GT aims to produce a well-arranged and organized theory that can be generalized. Constructivist GT from Charmaz focuses on an emerging theory or theoretical proposition through exploring and interpreting the experiences of a group of people in a local context (Singh and Estefan, 2018). More descriptions of a constructivist GT approach are provided next in this chapter. Each approach has slight differences in the analysis style that matches their focus and philosophical assumptions. However, all three approaches use constant comparison analysis as a core feature of conducting a GT. Similar approaches to the coding process are used for all three approaches, yet in Glaserian and Strausserian GT, the first stage of coding is referred to as "open coding" and "selective coding" for the next stage of coding. However, Strauss and Corbin have proposed an additional coding stage called "axial coding", which comes in between the open and selective

coding to reassemble and organize the initial data gathered (Glasser, 1999; Strauss and Corbin, 1990). On the other hand, in Charmaz's constructivists GT, the first stage is referred to as "initial coding" and the next stage as "focused coding", in which more analytical thinking and categorizing occurs for the most significant codes in the initial stage (Charmaz, 2006; Charmaz, 2014). Ultimately, all approaches seek to develop a core category that explains the primary concern of the phenomenon. Table 3.2 summarizes the differences between the three approaches of GT. The decision regarding the best GT approach for this study was based on the researcher's focus and philosophical position, which will be explored next.

Table 3. 2: Options of GT approaches

GT approach / Features	Glaser	Strauss and Corbin	Charmaz
Philosophical stance	Positivist stance, believes in researcher's objectivity and one reality.	Postpositivist stance, acknowledges that there are several realities. Researcher remains objective in data analysis.	Constructivist stance, believes in multiple perspectives. Researcher's engagement and interpretation are acknowledged.
Aim in developing a theory	To develop a theory that can be generalized in the wider context	To develop a theory that is well-ordered and thorough.	To develop a theory that explore specific issues in localised context.
Analysis	Constant comparison analysis through stages of "open coding" and "selective coding".	Constant comparison analysis through stages of "open coding", "axial coding" and "selective coding".	Constant comparison analysis through stages of "initial coding" and "focused coding".

3.4.3 Selecting Charmaz's constructivist approach of Grounded Theory

The rationale for choosing an appropriate research methodology was informed by the researcher's focus and philosophical assumptions, as identified earlier in this chapter. It was vital to have ontological and epistemological positions to select the most appropriate GT approach for this study (Singh and Estefan, 2018). Consequently, this section presents how the researcher's ontology and epistemology guided her use of Charmaz's constructivist GT approach.

Charmaz explained that her choice of the constructivist philosophy was to acknowledge the researcher's contribution in theorizing and to conceptualize the data. She believed that subjectivity is inevitable in data construction (Charmaz, 2014). In this way, the researcher's own experiences are valued and not denied (Charmaz, 2008). This ontological assumption was most fitting to this study. The researcher believed it was difficult to keep the personal experience of being a child health nurse away from any input in interpreting the data. The researcher's previous experience with young children as a child health nurse was the best motive to engage in interpreting the data gathered from the children and their parents.

The second reason for this study's use of Charmaz's GT was that it is a more flexible approach that provides an opportunity for multiple perspectives (parents' and children's) (Charmaz, 2014). The researcher's epistemological position was that the children and parents are the experts in something concerning the children (children's behaviour and emotions as they live with CHD). Furthermore, when previously working with children in clinical practice, the researcher noted the unheard voice of children; thus, the researcher was motivated to listen to children's views and understand their condition and related behaviour and emotions. So, conducting this study using Charmaz's GT was epistemologically suitable for the researcher, which led to

findings being focused on the voice of the children and their parents and included the researcher's interpretation of the participants' views.

The end product of conducting a study based on Charmaz's approach is to theorize data that are based on one or more perspectives as interpreted by the researcher (Charmaz, 2017; Khan, 2014) and generate a theory that critically explored a series of issues related to the researched area (Gibson and Hartman, 2013). Therefore, the theory produced by the constructivist GT has a depth and richness of understanding of a specified area and population and combines the participants' and researcher's experiences, which, as explained earlier, are consistent with this study focus and the researcher's philosophical stance (Charmaz, 2017).

3.4.4 Key processes of Grounded Theory

In addition to the usual process of conducting qualitative research, GT involves implementing several procedures that are uniquely followed to lead to an emergent theory. The rest of the chapter will briefly describe the key techniques of GT based on Charmaz's constructivist approach. More elaborations about these techniques in constructing this GT are presented in Chapter 4.

3.4.4.1 Theoretical sampling

Theoretical sampling is an essential technique of GT that guides the researcher in developing an emergent theory by further collecting data relevant to the emerging concepts and themes (Charmaz, 2006; Corbin and Strauss, 2015; Khan, 2014). The researcher needs to have themes or categories identified from the initial data; thus, they can test and refine them by making informed decisions about collecting further data, such as purposefully recruiting specific groups of participants or changing the study setting (Charmaz, 2014). Theoretical sampling and additional data collection are continued until the

core category emerges, and theoretical saturation is reached (Birks and Mills, 2015).

3.4.4.2 Constant comparative analysis

Another vital technique in GT is the constant comparative analysis which is about constantly comparing incidents, codes, and categories to each other and across each other throughout the GT process (Birks and Mills, 2015). This process begins with initial coding, emerging preliminary categories, then focused coding through an iterative comparative process of going back and forth to data while analysing, until a core category and theory are generated (Charmaz, 2006; Glaser and Strauss, 1967; Strauss and Corbin, 1990). The method of constant comparative analysis has an advantage of allowing the researcher to create complex and rich analytical thoughts by making connections and relations between the data throughout the study (Olson et al., 2016).

3.4.4.3 Theoretical saturation

Theoretical saturation occurs when the core category and sub-categories reach an advanced level of conceptualising (Birks and Mills, 2015). Their properties are significantly dense and deep, with no new concepts emerging with further data collection; thus, sampling is ceased (Glaser and Strauss, 1967). Theoretical saturation is an integral part of conducting GT, yet a very complex stage in which the researcher needs to have a level of conceptualisation for theory development and an experience in identifying points where saturation occurred (Breckenridge and Jones, 2009; Glaser and Strauss, 1967). This is different from what reaching saturation is about in other qualitative studies. Data saturation is more of a descriptive saturation, while GT's theoretical saturation is more conceptual (Breckenridge and Jones, 2009). Reaching theoretical saturation does not mean that no new stories or incidents arise from collecting new data; instead, it is about no new properties or patterns from the

identified incidents emerging; thus, until reaching this point, the researcher needs to pursue data collection (Charmaz, 2014; Glasser, 1999).

3.4.4.4   Theoretical coding

Coding is about assembling several data that resemble a concept or an understanding and giving them a name related to their shared concept (Gibson and Hartman, 2013). Initially, in his book "Theoretical Sensitivity", Glaser described coding in-depth and explained that theory development is based on the conceptual relationships identified from coding (Glaser, 1978). Once the initial and focused stages of coding are finished, a more complex level of coding called theoretical coding is followed (Charmaz, 2014). As described by Charmaz (2014), theoretical coding aims to theorize the focused codes, find conceptual relationships between the codes and categories, and guide the analysis toward theory development.

3.4.4.5   Memo-writing

Memos are what the researcher records about any analytical thoughts, ideas, or interpretations of the collected data. Memo-writing allows the researcher to advance analytical thinking and to progress from descriptive to critical thinking (Bryant and Charmaz, 2007). Memos are theoretical ideas of the codes and include initial and progressional thoughts of the codes and the relationships between them (Glaser, 1978). For the sake of developing a theory, researchers should constantly keep writing memos as the study progresses and gather as many thoughts and ideas that later will be sorted for writing-up the theory (Andrews et al., 2017).

3.4.4.6   Theoretical sorting, diagramming, and integrating

Sorting is a logical way to organise and refine memos of theoretical relationships between the categories, and, in GT, it takes the researcher to the level of theory development (Charmaz, 2014; Glaser, 1992). Diagramming can be images, maps or figures that allow visualising and demonstrating the

relationships and directions between categories which are helpful to utilise at several points during the analysis (Charmaz, 2014; Corbin and Strauss, 2015). Finally, integrating memos is about finding how the categories fit together, which helps find comprehensible relationships. The three strategies of sorting, diagramming and integrating are intertwined in serving the theory development and writing up the theory (Charmaz, 2014).

3.5 Summary

This study aimed to listen to children with CHD and their parents about their behaviour and emotions and understand their views by developing a theory using Charmaz's constructivist approach of GT. Moreover, this chapter provided an overview of qualitative research, GT methodology, different approaches of GT, and the main stages of conducting a GT study. The rationale for choosing Charmaz's GT for this study was the compatibility found between Charmaz's and the researcher's ontological and epistemological stances. Furthermore, Charmaz believed that researchers could and should have their interpretation integrated into the participants' views in analysis, which the researcher found helpful in this study, particularly with a background experience of working with children in health care contexts in SA. Also, this study found that Charmaz's approach is suitable because the aim of the study was to investigate more than one perspective, children and their parents.

Chapter 4 Research methods

4.1   Introduction

This chapter presents the methods used for implementing Grounded Theory
(GT) in this study, following Charmaz's approach to GT (Charmaz, 2014).
Descriptions of the study setting and the process for participants' identification
sampling and recruitment are provided. Then, methods of data collection and
analysis used in this study are also presented. Lastly, the ethical considerations
followed in conducting this study are discussed.

4.2   Context of the research population and setting

This research was conducted in Jeddah, Saudi Arabia, the researcher's home
town. Jeddah is the commercial capital of Saudi Arabia and the second-largest
city after Riyadh, the capital city. It is located in the west of Saudi Arabia on
the Red Sea, and it is close to the two holiest cities in the Islamic religion,
Makkah and Madinah. It is the principal gateway to Makkah, the first-holiest
city in Islam. Jeddah Islamic Port is the second-largest port in the Arab world.
Therefore, Jeddah hosts millions of Muslim pilgrims from all around the world
every year (World-Population-review, 2021). Accordingly, the location of
Jeddah city attracts Arab and Muslim populations from around the world,
which explains the multi-cultural and diverse nationalities of Jeddah's
population. The current population of Saudi Arabia is 34,813,871 people at the
mid-year 2020. Generally, the immigrant and foreign population in Saudi
Arabia make up 38.3% of the Saudi population in 2019 (The-World-Factbook,
2021), mostly from the neighbouring countries such as Egypt, Sudan, Syria,
Jordan, Palestine and Yemen. Foreigners in Saudi Arabia are also found from
other non-neighbouring countries such as India, Pakistan, Bangladesh,
Philippines, and Turkey. The mother language in Saudi Arabia is Arabic and

the religion of most of the population is Islam (World-Population-review, 2021).

Health services in Saudi Arabia are provided through the governmental sector from the Ministry of Health (MoH), and the private sector. The MoH provides healthcare services free of charge to all Saudi citizens, legal immigrants, foreigners, and all pilgrims and visitors to the two holy cities. The MoH healthcare services are delivered through general and specialist hospitals, and primary-healthcare centres located throughout the country (Saudi National Portal For Government Services [GOV.SA], 2021).

The current study was conducted in a university hospital in Jeddah, which is one of the largest tertiary care hospitals in the west region of Saudi Arabia. The paediatric department in the hospital includes paediatric inpatient care (paediatric medical and surgical wards, paediatric intensive care unit, paediatric cardiology intensive care unit, and neonatal intensive care unit), and paediatric outpatients clinics (OPC). This study was conducted, particularly, in the paediatric cardiology OPC, where children with congenital heart disease (CHD) are treated (n= 61 children newly diagnosed with CHD in the year 2020, which was an estimated number provided by one of the cardiologists in the hospital) with patients with a range of severities of CHD and diversity regarding Arab nationalities. Examples of the most common Arab populations are treated at the hospital, other than Saudi, are Yemeni, Syrian, Sudanese and Egyptian.

4.3   Participant identification and recruitment procedures

Potential participants were identified from the population of children with CHD, who were being followed up in the cardiology OPC at the hospital. Parents of children with CHD were automatically approached once their child was found to be eligible for the study.

For participant identification in the current study, three areas of the hospital were initially proposed for recruitment, which were paediatric (medical and surgical) wards, and paediatric cardiology OPC. Primarily, Paediatric (medical and surgical) wards were approached (in September 2018) with a plan to identify eligible families (children and parents) for the research, with the support of the head nurse of the wards, and to give them the Participant information sheet (PIS) before they made their decisions to participate. However, there was no response from the families identified from the wards at this stage, since children usually spent a few days to a week in the ward before getting discharged to be followed up in the OPC. It is also possible that because of the few days spent in the ward, and being busy with their hospitalised children, the families might have had difficulty in considering study participation.

Therefore, paediatric cardiology OPC was considered to identify eligible families during the period 7th October 2018 to 23rd July 2019. The researcher designed a recruitment plan where the families could be interviewed on the same day as their children's appointments at the OPC. This was achieved by contacting the families a week before their children's appointments. In this phase, more families agreed to participate and were recruited within a shorter time scale. Initially, the researcher visited the cardiology OPC several times to introduce herself to the nurses and the Cardiologists; these introductions facilitated the process of gaining their assistance in identification of the eligible families.

To identify the families from the paediatric cardiology OPC, the researcher accessed children's appointments' lists, profiles, and parents' contact information from the hospital database with permission from the Research Ethics Committee at the hospital, and the School of Healthcare Research Ethics Committee (SHREC) at University of Leeds (UOL), reference number HREC17-045. The permit to accessing the hospital database was facilitated by

the fact that the researcher is employed in the university as a lecturer and has access to the hospital's units for educational purposes. Afterwards, the researcher checked the children's profiles against the inclusion criteria to decide on their eligibility. Children diagnosed with CHD aged 4-10 years old were two of the main criteria. Further information on the inclusion and exclusion criteria are discussed next.

For the process of participant recruitment, two versions of the participant information sheet (PIS) were created, one presented in simple Arabic language for the parents, and the other one designed in a colourful format and simpler style to be developmentally appropriate for the children (aged 6-10 years old). The PIS included brief information in the Arabic language about the purpose of the research, the need to interview the parents and their children, the advantages and disadvantages of participating in the research, confidentiality, and the right to withdraw from the research at any time. The English version of the PIS is presented in Appendix-IV. Children in Saudi Arabia usually start to read in grade one of primary school at the age of 6 years old. Thus, the children's PIS was provided to recruit children who were aged six to ten years old; when children younger than six years old were recruited, the researcher asked the parents, once they had read their version of the PIS, to discuss and explain the children's version of PIS. Moreover, alongside providing the PIS, all eligible participants were offered the option to ask for further information about the research and were reassured that their decision on participation would not influence their children's treatment at the hospital.

To contact the eligible families, a week before their children's scheduled appointments, the researcher sent text messages to the parents' telephones about the research with an attached PIS as an electronic document. The messages were sent via WhatsApp (mobile application) to the same number for the parents (WhatsApp is widely used in Saudi Arabia, and most people find it convenient for communication). The messages with the PIS were sent

to the eligible parents' telephones in the Arabic language, so that they could read it before making their decision on participation; the following is the English translated version:

"Hello,

My name is Nada. I am a PhD (Doctor of Philosophy) student working with the doctors and nurses in the paediatric cardiology department at (hospital name), studying the behaviour and emotions of children who have congenital heart disease, through a short research discussion/ interview with the mother or father, and another discussion with the child themself. I am messaging to invite you and your child to take part in my research. I note that you have an appointment in the outpatient department at the hospital on (Date/Time). Please see the attached file for further details. If you are interested in taking part, please message me to say this and I will contact you to arrange to meet you in the OPD on the appointment day, at a time convenient to you. Also, please ask your child to read the other file (designed for 6-10 years old) or explain to them briefly about the research if they are 4-5 years. [for each family I deleted the option that was not relevant]. If you would like to ask me questions before deciding, please message me, and I can either ring you at a date/time convenient to you before the appointment date or talk to you at any time during the day of the appointment. If you decide to take part, I will meet you and your child during the day of your appointment. You can also, choose to be interviewed by phone, if this is convenient for you. However, the child has to be interviewed face-to-face.

Thank you for reading this."

For those who did not reply to the message with questions or their decisions on participation, the researcher followed up with them by sending follow up messages a day or two before their child's appointment to check on their decisions. In some cases, no reply was received even after sending the follow-up messages. In those cases, on the date of the children's appointment, the researcher approached the families personally at the OPC to check on their decisions.

4.4 Sampling procedures

Children with CHD and their parents were sampled using two sampling strategies, purposive sampling followed by theoretical sampling, respectively. Purposive sampling was used to recruit initial participants of children and their parents based on specific characteristics of the children, which, then, aided theoretical sampling. GT methodology provides the researcher with flexibility in selecting the number of participants without specifying in advance which allows the researcher to focus on being analytical and generate a theory (Charmaz, 2014). Moreover, the researcher needs to rely on developing theoretical concepts and deciding if further participants are required (Corbin & Strauss, 2015). Hence, the final number of families recruited was determined by the concept of theoretical saturation and data saturation. Initially, the researcher decided to recruit approximately 8-15 child/parent dyads, as data saturation according to Guest et al. (2006) can be achievable with up to 12 participants. Further information around data and theoretical saturation is discussed later in this chapter.

4.4.1 Purposive sampling

In GT studies, the researcher initially can choose participants who have generally experienced the studied field following a purposive sampling strategy, which then guides the theoretical sampling of participants who contribute to building theory (Creswell & Poth, 2018). Purposive sampling is

when the researcher handpicks the participants who match specific characteristics to be included in the study (Creswell and Clark, 2017). Thus, as the sample, in the current study, was selected from a specific group of children and their parents, the initial sample was considered using a purposive sampling strategy. The sample was selected from a population of children with CHD based on the gap found in the literature review (Dahlawi et al., 2020). In sampling initial participants, the inclusion criteria below were followed:

- Children of both genders aged 4-10 years old with CHD, to address the identified gap in the literature about the age group of children with CHD, and their behaviour and emotions.
- With varieties of CHD complexities and treatment procedures (cardiac surgery or cardiac catheterization), to collect perceptions from as broad a group of children with CHD as possible. Also, to identify any possible relationships between different CHD complexities and the behavioural and emotional status of the children.
- One parent of each eligible child. The perception of the child is the main focus in this research; thus, proxy reports from only one parent per child were considered sufficient. Parents were provided with the opportunity to choose whether the mother or the father would participate.

However, certain criteria were also followed to exclude child participants as follows:

- Any child with acquired heart disease or with CHD combined with diagnosed syndromes or genetic disorders (e.g. Down Syndrome, Autism, or Kawasaki disease), acquired heart diseases (e.g. Rheumatic heart disease), physical or mental disabilities, or psychological disorders, to avoid a possible limiting effect of these disabilities and diseases on the findings.

- Non-Arabic speakers (e.g. Indian or Pakistani) who live in Saudi but seldom speak Arabic or English languages (Table 4.1).

Table 4. 1: Participants' inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Children's age and gender	Male and female aged 4-10 years old.	Children younger than 4 and older than 10 years old.
Children's diagnosis	Diagnosed with CHD, who are pre-, or post-surgery or cardiac catheterization.	Diagnosed with: - acquired heart diseases. - syndromes or genetic disorders. - physical or mental disabilities. - psychological disorders.
Language	Arabic speakers: Saudi and non-Saudi residents.	Non-Arabic speakers e.g. Indian or Pakistani.
Parents	One parent of each eligible child.	

4.4.2   Theoretical sampling

The shift from purposive to theoretical sampling in GT was described by Draucker et al. (2007) as being a consecutive process, by which the researcher can start generating a theory. It, also, enables testing of the emergent concepts and theories from the data and allows the recruitment of new participants or a change of setting to collect further data (Pope and Mays, 2020). Accordingly, in the current study, theoretical sampling was informed by analysis of the initially collected sample and a sampling frame. To analyse the initial data collected, the researcher paused collecting data to analyse them. Also, a sampling frame was developed to demonstrate all the sampled participants and their specific criteria, such as diagnosis, disease severity, age, and gender,

which helped to inform further participants to recruit. The sampling frame was then used in developing a table for participants' characteristics (see chapter 5). Concurrent to the theoretical sampling, the interview questions were modified according to the analysis of the initially collected data (Appendix-V). Thus, theoretical sampling was achieved by providing the additionally recruited participants with the opportunity to elaborate more about certain aspects that were generated from analysis of the initial data. Moreover, further participants were approached for recruitment based on the initial data analysis.

4.5   Data collection methods

Following the GT guidelines, data collection and analysis in this study, were conducted using an iterative process (Charmaz, 2014). This section presents the data collection methods followed in the current study. Next, is a description of the data analysis methods and procedures.

4.5.1   In-depth interviews

Interviewing participants helps the researcher to go deeper into meanings and to expose new and unknown ideas or topics related to a certain topic (Pope and Mays, 2020). According to Brinkmann (2013), interviews are about conversations and discussions that individuals use to exchange knowledge and experiences. In qualitative research, the way these conversations are conducted depends on the form of the interview. Interviews can range in terms of structure (structured, semi-structured, and unstructured interviews), and interviews can be of individuals or groups (Brinkmann, 2013). Moreover, to conduct interviews, it is essential to select a type of interview in order to prepare for the interview. For example, the one-to-one interview can be undertaken in person as a face-to-face interview, or one-to-one and remotely using the telephone (Creswell and Poth, 2018).

Face-to-face interviewing has an advantage of allowing the researcher to notice the non-verbal interaction of the interviewee; for example, the interviewer can re-state the question if the interviewee looks confused or unable to answer (Irvine et al., 2013). Moreover, open-ended and in-depth explorations of the participant's view fit the method of GT, in which the emergence of related theories is facilitated (Charmaz, 2014). Qualitative interviews, mainly semi-structured interviews, as opposed to structured interviews, are suitable when answering exploratory research questions, when there is a need to deeply understand participants' views and experiences (Mason, 2018). Thus, the form of semi-structured interviews was chosen to capture the behaviour and emotions of 4-10-year-olds with CHD, and the way the parents perceive their children's behaviour and emotions.

The total number of interviews conducted in the current study was 20, all were in-depth and semi-structured interviews conducted face-to-face or by telephone, in Arabic language. From the 20 interviews, ten interviews with children were conducted face-to-face by the researcher. Among the ten parent interviews, seven were interviewed face-to-face, and the other three parents were interviewed via the telephone as was the parents' preference. Interviews varied in duration; those with parents ranged between 38:11 minutes to 1:13 hours; the longest interview was with a father of a ten year old male. Interviews with children ranged between 28:07 minutes to 1:10 hours; the longest interview with children was with an eight year old girl.

All face-to-face interviews, for both parents and children, were conducted in in a classroom at the paediatric cardiology OPC at the hospital in Jeddah. Prior to the interviews, the researcher arranged with the head nurse to book a classroom at the cardiology OPC for two hours. The researcher followed up with the recruited families through the telephone and confirmed the interview's time, which was on the day of the children's appointment at the OPC. Once the family arrived at the OPC, the researcher met the family in the

waiting area and checked the preference of the family to be interviewed before or after their child's appointment. Since some of the families had to wait for laboratory results before seeing the doctor, they found it convenient to be interviewed before their child's appointment with the doctor. Other families wished to be interviewed after all check-ups, doctor's appointment, and laboratory tests were completed. Accordingly, the booking of the classroom was re-arranged with the head nurse. No conflicts were raised when re-arranging the booking time of the classroom. Only once, when the classroom was booked for educational purposes, the head nurse arranged for the use of another room for the interviews.

The choice of telephone or face-to-face interviews was given to parents concerning their time restriction. Thus, telephone interviews were conducted for those who expressed difficulty with availability at the OPC for the face-to-face interviews. However, the researcher explained the need for their child to be interviewed face-to-face on the day of their appointment for the application of Arts-Based approach. Then, the researcher contacted the parents through their contact numbers to plan times convenient for interviewing them using the telephone. A day before the telephone interview, the researcher followed up with the parent to confirm the interview time. Verbal consents were obtained by the researcher on the telephone prior the interview. All three telephone interviews were conducted at the parent's convenience, and no technical issues arose. Indeed, Holt (2010) found that telephone interviews were convenient for participants who have a very busy life, which was similar to the situation of the participants in this research. It can be anticipated that a telephone interview may cause lack of control for the interviewer or may easily induce unavoidable distractions by the interviewee's surrounding environment. However, it was found that using the telephone for interviews provided parents with control over interacting with their children and minimized interruptions by merely instructing them not to disturb (Holt, 2010). Similar to the current study, parents who were interviewed by telephone were in control

of planning the appropriate time and place where fewer or no distractions could be induced.

For all dyads, child and parent had separate individual interviews to avoid any possibility of the child developing emotional harm or distress when parents were talking about their children and reporting children's behavioural and emotional issues. The researcher obtained the informed consents and revisited the confidentiality and privacy considerations prior to the interviews. However, children and their parents were provided with opportunity to make a choice about parents' presence during the child's interview. Half of the children (n=5) did not mind being interviewed without their parents' present. The other children wished to be interviewed with the parents present. Ethical considerations regarding parents being present during their children's interviews are discussed in section 4.8.3 in this chapter.

The researcher considered obtaining parents' proxy reports about their children to aid supporting or building on information obtained from children's self-perception; thus, this could achieve a broader understanding of children's behaviour and emotions. Recent studies have found that by exploring parents' proxy reports of their children's health-related quality of life, valid information about their children was obtained which contributed to better understandings of the children's conditions (Abate et al., 2018; Hornsby et al., 2017; Lifland et al., 2018). However, researchers should avoid using parents' proxy reports in isolation from children's self-reports about children's health conditions, since differences in child-parents' perceptions were identified (Abate et al., 2018; Hornsby et al., 2017).

To guide the interviews, interview topic guides were used. The children's interview topic guide was designed to be appropriate to their age and developmental stage. Parents' face-to-face and telephone interviews were conducted using another specific interview topic guide. The main purpose of the interview topic guide is to formulate the interview questions in a way that

is understandable to the interviewee, guided by the research question and aims (Creswell and Poth, 2018). The topic guides, in the current study, were designed to cover and address the aims and objectives of the study, and comprised six main topics, including the welcoming and closing questions (Appendix-V). Moreover, the topics and questions for the interview were designed based on the researcher's experience as a child health nurse, and from reviewing the literature. From the literature review, commonly used checklists for assessing children's behaviour and emotions were identified (e.g. Child's Behavioural Checklist) (Achenbach, 2001), which the researcher reviewed to aid the construction of some of the interview questions for children and parents. Further description of the children's interview questions is presented next in this chapter. For parents' interviews, the initial or warming-up questions were broad and designed as open-ended questions to encourage engagement in the conversation. Parents were then asked about the behavioural and emotional status of their children and issues at home and school, for example, how did the parents deal with these issues and what was the child's awareness of the conditions and the child's feelings towards their heart condition (Table 4.2).

Moreover, follow-up questions were added to gather detailed answers from the participants, for example, "when was your child diagnosed?", and "what was the treatment plan?". Probing questions, for example, "why?", and "how?" were used to pinpoint clarity and further explanation from the interviewee. Probing during the interview can help the researcher to ask for details in a certain context, and, thus, generate themes in that particular context (Saks and Allsop, 2012). Besides probing, the researcher asked questions starting with "how and what", which, as described by Charmaz (2014), enhances the researcher's analytical sharpness by enabling participants to elaborate; thus, the researcher creates links between events and stories at an early stage in the research. As the interviews progressed, the discussed topics became more focused on the issues that most concerned the participants rather than adhering

strictly to the topic guide, which helped to avoid preconceptions about emergent issues. This is also a characteristic when conducting semi-structured interviews (Mason, 2018).

Table 4. 2: Examples of interview topic guide questions for parents

Interviewee	Topic	Example
Parents	Warming-up questions	-"Tell me about your child's heart condition?" -" What do you know about CHD?"
	Child's behaviour and emotions at home	-"How would you describe your child's behaviour at home?" -"How do you think your child feels about his/her condition?"
	Child's behaviour and emotions at school, school performance, and socialisation	-"How does your child's teacher describe him/her at school?" -"Would you describe your child as a social child? Why?"
	Child's support	-"What can you tell me about how your child is dealing with having CHD"?

Every interview was audio-recorded; the importance of the audio-recording was discussed with participants prior to attaining informed consent. Further ethical considerations are discussed later in this chapter. It is vital to record the interviews to be able to reach accurate data representation and gain sensitive meanings and interpretations (Mason, 2018). Digital recorders offer high-quality sound recordings, which can easily and safely be stored on and transferred to a range of devices (Southall, 2009). Thus, audio-recording in this study was done digitally using a smart mobile phone that was allocated to the researcher only for research purposes. The smart mobile recording has an

advantage over a digital recorder as it facilitated transferring data directly to the secure M-Drive of the University of Leeds, where all data from this study were stored. Using the internet, the researcher uploaded all interviews to the M-Drive immediately after the interviews, rather than transferring the data to a computer then uploading to the M-drive, which saved time and effort, and ensured participants' privacy. However, the researcher also kept another digital recorder as a back-up for the mobile recording. It was crucial to overcome the challenge of any technical problems with the mobile's digital recordings, such as a breakdown of the recording; thus, two recorders were considered. Further discussion about data storage and privacy is provided later in this chapter in section 4.8

For analysis purpose, the researcher transcribed the interviews and translated from Arabic to English by listening repeatedly to the recording of each interview. Initially, for the first four interviews, the researcher transcribed the interviews in the Arabic language, which consumed up to six hours each, followed by another six hours of translation from Arabic to the English language for each interview. The time needed for this was a concern, and it was agreed with the supervisors to transcribe the remaining Arabic interviews into English directly. The researcher listened to the audio recording of each interview in Arabic and transcribed it into English directly, which also allowed more time later on for the researcher to immerse herself in the data and analysis. Accordingly, the researcher transcribed the rest of the 16 interviews directly into the English language, which saved six hours of translation per interview. In addition, it was valuable for the researcher to self-transcribe and translate the interviews to enhance analytical thoughts and allow the writing of memos about the initially generated codes and categories.

4.5.2   Interviewing children using an Arts-Based approach

One of the main objectives for this research was to hear the children's views concerning their behaviour and emotions; as discussed by O'Reilly and Dogra

(2016) it is encouraged for children's voices to be heard when conducting research involving children. Furthermore, a report by National Voices (2015) emphasised the need for children's and young people's voices to be taken into account and to be respected in making their own decisions. Essentially, the right of the child to be heard by expressing their views, thoughts and feelings about something affecting them, has been recognised by the United Nations Convention on the Rights of the Child (UNCR, 1989). The convention enhanced the value of children's views and improved the way others regarded children's thoughts and ideas (O'Reilly and Dogra, 2016). For the children's voices and views to be heard, the researcher has a role in acknowledging the importance for children to express their thoughts, ideas, and opinions by adopting children's accounts in research (Greig et al., 2013). The value of children's views and perceptions in the contribution to knowledge about children's lives and environment, is paramount. Therefore, researchers should involve children's views in research (Lewis, 2010). Hence, recent studies have employed advances in researching with children and in doing so have empowered the children by listening to their voices, by asking them directly about their views, and/or by including them as participant researchers in researching aspects of concern to themselves (Greig et al., 2013; Lewis, 2010; O'Reilly and Dogra, 2016).

Based on the interest of the researcher to hear children's voices about their behaviour and emotions, and the gap found in the literature review (Dahlawi et al., 2020), children in this study were invited to provide their perceptions through face-to-face, semi-structured, and in-depth interviews. To ensure accuracy in children's responses during the interviews, and their ability to understand the research topic and interview questions (Greig et al., 2013), the researcher included children in this study who had no cognitive or developmental impairment. Furthermore, the researcher considered age and developmental stages when designing interviews for the children. Based on Piaget's cognitive theory (Piaget, 1964), the cognitive stages of children

participants in the current study are in between the stages of pre-operational (2-7 years old) and concrete operational (7-11 years old), where they start to learn to verbalise distinct words and sentences and their memory and thinking process develop. Thus, developmentally appropriate methods were considered in interviewing the children. Further discussion on children's cognitive development is provided in section 11.4.1 in Chapter 11.

Arts-Based approaches were used, when conducting face-to-face interviews with children in the current study, which are appropriate methods for the children's developmental stage. Face-to-face interviews offer a great opportunity to let the child actively engage in the interview using participatory techniques during the interview (O'Reilly and Dogra, 2016). In addition, Arts-Based approaches are usually used in interviewing children to help encourage them to talk and express themselves. Arts-Based approaches are identified as child-oriented approaches as they fit with the children's daily life activities, skills, and capacities (Carter and Ford, 2013). In this study, children were invited to draw on a blank piece of paper and use their drawings to help them explain their feelings and behaviours. The Arts-Based approaches worked efficiently with children who enjoyed drawing and using pictures which were provided to them during the interviews. Using pictures of faces such as emojis, as well as asking the child to draw their faces to convey what they feel about a particular topic was found to be effective among children in school settings (Due et al., 2014). One example is a study that involved children aged 4- 5-years old, who were hospitalised for minor procedures; they were effectively engaged during the interviews through using drawings, which acted as an ice-breaker tool for the children to feel relaxed and talk naturally (Swallow et al., 2007). Hence, the researcher in this study initiated the children's interview with a drawing activity to attract the child's attention and engagement with the interview. Then, children were asked to draw themselves and to talk about what the child in the picture looks like or feels. Moreover, pictures of a hospital, doctors, nurses, and hearts were used to help the child express

feelings towards each picture. Pictures of emojis with emotional expressions of being happy, sad, crying, or angry were also shown to the children, and they were asked to pick the face that best expresses their feelings towards different situations or places related to their CHD condition. For example, the children were asked how they felt about the pictures of the heart, or hospital. Children usually pointed at the face that resembles their feelings, especially if they did not know how to express it in words (picture 4.1).

Picture 4. 1: Art-based approach tools for children's interviews

Children interpreted the emojis and the other pictures according to what they meant to them. Certain faces of emojis are meant differently to some children. For example, the researcher asked a child about how getting tired easily made him feel. The child chose a sad face, but when the researcher asked what this face meant, the child perceived it as an angry face. Therefore, it was vital to ask the child each time they picked a face to check what exactly was the feeling they were expressing. Likewise, pictures of hearts were interpreted differently by children. For example, one child chose a small size heart which was according to him resembling his heart as being a child and his dad would have the picture of a bigger size heart. Another child picked a pink heart because she loved the pink colour. Even though the researcher intended to show the pictures of the heart to introduce talking about the CHD, not all

children talked about their heart condition directly when selecting their heart pictures. Some have introduced talking about their condition when asked about what were the things that concerned them, or what were the things that they don't like about themselves. For instance, the child who mentioned becoming easily tired said that this was something he did not like about himself, the researcher was then able to probe using questions like "why", or "what is it about getting tired?". Then, the child started to talk about the CHD and the discussion about the condition was initiated.

While some children preferred to use pictures and emojis to describe themselves, others preferred only to draw. The researcher allowed the children to choose and direct their preference in using the available tools of the Arts-Based approach, after introducing the tools to them. For the children who preferred drawing only, they liked to draw while talking throughout the interview. Indeed, some children were more involved in free drawing than talking. In such cases, the researcher suggested drawing for a few seconds, then to stop and talk. Also, the researcher directed the children's attention toward drawing things related to the interview's points of discussion. For example, drawing their house, school, family members, friends, hearts, their doctors, or hospital. The researcher then was able to talk to the child about related topics while letting the child use their drawing interest.

When both parent and child were to be interviewed face-to-face, the researcher asked the family to interview the child first and then their parent to ensure adequate time available for the child to warm-up and engage in the interview. Besides, as the researcher required time to set up for Arts-Based approach used for child's interviews, starting with interviewing the child was found more appropriate. Before starting the child's interviews, the families were asked about their wishes as to whether or not their child could be interviewed without the presence of the parents, as described earlier. Once the child's interview was completed, the parent was interviewed face-to-face in the same

classroom. The researcher offered the opportunity to take a break prior the interview, if the parent wanted a break. During the parent's interview, the child and the other parent were asked to wait in the play room or waiting area.

Despite the preferences for such children's participatory methods in the literature, Waller and Bitou (2011) have highlighted that the application of these methods can be challenging as the child's participation in the research, more or less, depends on the research design and on building a researcher-child relationship, more than the participation activity itself. This was managed, in this study, by spending pre-interview time with each child to build trust and a relationship. The researcher used the first few minutes of every child's interview to identify the language and terminology familiar to the child by asking general warming-up questions, such as "what is your favourite colour?", and offering the opportunity to freely draw anything they like. The researcher being friendly to the child and allowing the child to become familiarised with the environment or tools used for the interview (e.g. colours and pictures), can ease children's engagement in the interview (Greig et al., 2013). Following these strategies, the researcher was able to initiate a positive child-researcher relationship, and progress to attracting the child's attention to engage in the interview.

Arguably, another challenge in this context is the tendency for the data produced by a child in an interview (for example, drawing) to be interpreted according to the researcher's (an adult) point of view, where the researcher might interpret the meanings of the drawings without referring to the child's story of that drawing (Waller and Bitou, 2011). However, this challenge was managed in the current study by making sure that children's interpretations of their drawings were to be viewed through their verbal insights, and the researcher avoided miss- or over-interpretation (Carter and Ford, 2013). Therefore, the researcher asked the children about their drawings; for example, "why did you draw this", and "what is this drawing about?". The researcher

also clarified to the children that there were no right or wrong answers and that the researcher was only interested in listening to them. This helped the researcher to get the child's insights about the drawings and pictures regarding any discussed topic during the interview.

Prior to the study's interviews, three pilot interviews were undertaken by the researcher with three healthy children of friends. All were male, one was aged eight years, and two were six years old. These pilot interviews provided an insight on how to improve the study's interview questions and how to let the children engage in the interviews effectively. It was identified that spending a few minutes with the child prior to the interview would assist the child in engaging in the interview more easily. Moreover, drawing, colouring, and showing pictures showed effective encouragement of the child to speak openly and freely express thoughts. It was also found that children and the interviewer sitting on the floor to draw meant that the children would appear more comfortable and it reduced the sense of formality during the interview. These learned strategies of children's interviews informed the conduct of the actual research interviews, later on.

4.5.3   Patient and public involvement in research

Patient and public involvement (PPI) in research is referred to when the research is conducted by the public, not as participants but as contributing to designing, conducting, and /or disseminating the research (NHS, 2022). PPI is something encouraged and recommended by NHS as it is identified to produce well-designed studies, since the researched topic is more relevant to them, and they can help in conducting and disseminating the research in a more acceptable and understandable way to the participants (NHS, 2022) . Furthermore, public involvement is widely recognised as a crucial element in the research and receiving research funding in many countries including the United Kingdom, United States of America, Canada, and Australia (Absolom et al., 2015). Gray-Burrows et al. (2018) is an example of a study conducted in

the United Kingdom which included PPI in planning, conducting, and sharing the results of the study. The study provided a framework with a set of roles for PPI to enhance its implementation in research (Gray-Burrows et al., 2018).

Even though PPI is highly recommended for researchers, it was unfeasible to implement in the context of Saudi Arabia (SA). The researcher felt that the public and patients in SA need to be introduced first to such type of research, as some of the participants were unfamiliar to research interviews and listening to participants' experiences. Since the public in SA are more familiar with quantitative research and filling up a survey or questionnaire, qualitative research was something new to implement at least for the approached participants at the hospital in Jeddah. The researcher noted, during data collection, that many participants inquired about the qualitative research and the need for being interviewed, which indicated the need for introducing qualitative research as a priority prior to implementing PPI in SA. Moreover, talking to young children and asking them about their perceptions is also considered a new concept in SA, and the researcher had to explain and introduce the need for it to the families. Thus, the researcher suggests a need for enhancing the awareness of public and healthcare providers in SA about the importance of implementing PPI in future research and its impact on public benefits.

4.6   Data Analysis

In accordance with Charmaz (2014), the researcher followed the guidelines about data collection being simultaneous with data analysis; this included coding, memo-writing, constant comparisons, theoretical sensitivity, and categorising and theorising. These are discussed in more detail below.

4.6.1   Transcribing and translating process

In this study, all interviews (n= 20) were fully recorded in Arabic. The researcher transcribed and translated all of the interviews. Further description of transcriptions and translation are provided in in the next chapter (see Chapter 5).

4.6.2   Coding process

The coding process was conducted in English and was started as soon as the transcription of each interview was completed. In line with Charmaz's approach (2014), the researcher first implemented the two main phases of coding: initial coding, and focused coding, followed by theoretical coding to aid theorising the categories and emerging theory (Charmaz, 2014). The following process was undertaken for both parents and children's interviews.

According to Charmaz, the emphasis in coding is to find codes that are close to the participant's perspectives in the researched area (Gibson and Hartman, 2013). Therefore, at the stage of initial coding, the researcher read and re-read the transcripts to familiarise herself with the data and fully immerse herself in the families' experiences. The codes were generated by breaking the data into components and finding patterns within them. The initial codes were simple, open, comparable to each other, and close to the data (Charmaz, 2014). Then, the researcher added the description and meaning of each code on the margin of the transcript. The researcher started line-by-line coding by manually labelling the emergent codes from the interview's transcript. The line-by-line coding technique can help in finding implicit meanings in the data, and, also, comparing and suggesting links between data (Charmaz, 2014). At first, the researcher attempted to use the NVivo programme to sort and group the codes. However, it was recognised that importing each transcript into NVivo and spending time to highlight and create groups in NVivo would slow down the coding process. Instead, the researcher started sorting the codes manually using a Microsoft Word document by creating headings of each code with

description, memo, and related verbatim quotations from the transcripts underneath. Once the initial codes of each interview were generated, codes were compared with other codes to foster the constant comparison method.

At the stage of focused coding, in a separate Word document, the researcher used the initial codes to create more focused codes by constantly comparing and connecting between the codes, then grouping and categorising. Focused coding is about moving the most significant initial codes to a further analytical direction (Charmaz, 2014). The categories, at this stage, were more representative of children's perception of their behaviour and emotions. Connections and links were also made between the children's perceptions and their parents' proxy reports to build on the categories. The researcher used tables and mind maps to find connections between the categories and integrate them together (Appendix-VII). At this stage, the researcher integrated her interpretation of the data gathered from children and parents based on her personal experience and knowledge as a child health nurse. Moreover, in line with Charmaz's approach, the researcher, during the analysis stage, re-visited the literature regarding, for example, the behavioural and emotional status in children, and children with long-term conditions, which assisted the process of scaling up the analytical thoughts. Categories were reformed and changed as comparisons between category-to-category were progressed. Then, the categories were grouped into subcategories. Afterwards, the researcher used the focused codes to move towards theoretical coding, in which more analytical and conceptual thinking was adopted. Theoretical coding aims to theorise the data by developing a more coherent and comprehensive analysis (Charmaz, 2014). Using theoretical coding, the categories were transformed into more defined categories and integrated under a core category that represents the main concern of the children with CHD regarding their behaviour and emotions. Presentation of generated categories is provided in Chapter 5.

4.6.3   Constant comparison analysis

Constant comparison analysis, as described in chapter 3, is about constantly comparing each data excerpt with another to be grouped together according to their similarities, forming a concept heading (Corbin and Strauss, 2015). In this study, the constant comparison analysis method, which is one of the unique structures of GT methodology, was used in every step of data analysis, and until the last phase of analysis was completed and the substantive theory had emerged. The researcher applied this method by comparing code-to-code, code-to-category, and category-to-category across children's and parents' interviews. Data were also compared between the perceptions of child-to-child, parent-to-parent, and child-to-parent. Moving from-to the data and analysis repeatedly, stimulated the researcher's ideas and, thus, resulted in an original analysis (Charmaz, 2017). Also, the data were compared to the memo and the diagrams throughout the analysis process. The process of constantly comparing the data helped validate the emergent categories as more data were collected through theoretical sampling (Khan, 2014).

4.6.4   Memo-writing and diagramming

In this study, memos were kept to examine pre-requisite ideas throughout the analysis process. The researcher used memo-writing from the beginning and at every stage of analysis. Writing memos from an early stage allowed the researcher to write down initial thoughts about the generated codes and categories and to stay connected to the data. Moreover, through memo-writing, the researcher can make comparisons between the data and make links between the comparisons made (Charmaz, 2014). Consequently, the researcher wrote memos for each code and category and wrote any potential connections and relations between them, which helped to progress the analysis and eventually generate categories and a core category.

Also, the researcher implemented the diagramming method during the analysis process, in which diagrams and mind maps were created to represent the codes

and categories, and relationships between them. Making diagrams and clustering, as described by Charmaz (2014), is about sketching the preliminary codes and categories in circles and drawing connections between them to find relationships and similarities. At different stages of analysis, the researcher created several diagrams and used them to make connections, and compare between the data. The researcher created a spider map where the codes were presented in circles and tried to find connections between them to sort them under one category. Eventually, the researcher was able to generate categories from the data, find relationships between them and connect them to the core category, which then facilitated the emergent substantive theory (see Chapter 10).

4.6.5 Data saturation

Data saturation is when the researcher has achieved redundancy, and no new information is being obtained (Polit & Beck, 2010). In GT, theoretical saturation is when no new theoretical conceptions are presented when collecting more data (Charmaz, 2014). Data saturation in this study was reached when no new concepts or categories emerged; further data collection ceased at this point. Reaching theoretical saturation involved re-visiting the interview transcripts and field notes, sorting memos, and having discussions with the supervisors. After implementing theoretical sampling, the newly collected data were compared with the emergent codes and categories, in which it was found that all new data were conceptualized under the emergent categories and no new concepts or categories were emerging. Moreover, to decide on reaching saturation, the researcher revised the interview topic guide, research aim and objectives, and the emergent patterns and concepts; in this process it was identified that all points were covered and there would be no additional value in collecting more data. Throughout this stage, the researcher continued memo-writing in-line and reviewing previous memos and diagrams.

4.7   Theoretical sensitivity

To be sensitive theoretically, the researcher has to remain open to any ideas and meanings from the literature explaining the generated theory and to be able to find relationships and integration between the codes and categories (Gibson and Hartman, 2013). Theoretical sensitivity was developed throughout this study by constantly comparing the data to data and to the existing literature. Moreover, in the process of theorising, the researcher re-visited the literature to examine what was already known on the scope of the generated categories, which helped in maintaining theoretical sensitivity and validated the emergent categories by comparing the existing literature with the generated categories. As Charmaz's approach of GT advises the researcher to review the literature at any stage of conducting a research study (Charmaz, 2006), the researcher in this study visited the literature throughout the analysis stages, which allowed her to evaluate the data from several points of views, as acknowledged by Charmaz (2006). The researcher followed Charmaz's guidance on developing theoretical sensitivity by constantly asking questions about the links and relationships between the codes and categories, pausing, re-thinking from different viewpoints, and building on the ideas (Charmaz, 2014). Moreover implementing memo-writing and constant comparison methods facilitated the generation of categories and the core category that are grounded in the data and that are theoretically sensitive. Through ensuring theoretical sensitivity throughout the data collection and analysis stages, the researcher was able to reach a deeper level of theorising, which then aided generating a substantive theory (see Chapter 10).

4.8   Ethical considerations

This research was reviewed and approved by the School of Healthcare Research Ethics Committee (SHREC) at the University of Leeds (UOL) (reference number HREC17-045), as well as the Ethical review Committee of

the participating hospital in Jeddah, Saudi Arabia. As described, due to changes at stages of recruiting and identifying participants, two ethical amendments were submitted and approved (Table 4.3).

Table 4. 3: Stages of ethical amendments

No.	Ethical amendment	Reasons for amendment	Approval site/ Date
1st	Adding the paediatric OPC as a study setting at the hospital in Jeddah	No eligible participants were identified from the paediatric wards	Approved from both SHREC and hospital in Jeddah in October 2018.
2nd	After two months of recruitment, amendment to the process of approaching participants in the OPC	To expand the chance of eligible participants' recruitment	Approved with favourable opinions from SHREC in February 2019.
3rd	Adopting telephones interviewing as an optional data collection method, besides the option of face-to-face interviewing.	Some parents requested a telephone interview because of time restrictions	Approved from SHREC in May 2019.

Then, the researcher followed the ethical consideration of informed consent, confidentiality and autonomy to support the research participants as demonstrated by Polit and Beck (2010). Moreover, special ethical considerations for researching with children were undertaken.

4.8.1 Informed consent

Once the participants agreed on participation and before the interviews, the researcher obtained the written informed consent of all parents and ensured that they had read and understood the PIS, and were offered a chance to ask

questions or request more explanations. The purpose of the research was briefly explained verbally and in the PIS, before the participants' enrolment. According to Mason (2018), the researcher should make sure that the consents are sincerely informed by the participant by assuring that they understand what would be involved if they do consent to participate. In this research, the points of informed consent taken from the parents were about confirming that they had read and understood the PIS, that their participation is voluntary, and that they could withdraw from the research at any time without giving reasons, and the researcher would ensure the privacy and confidentiality of all information provided by them and their children. Finally, they signed their participation agreement. The English version of the consent form for parents is provided in appendix-VIII. The points in the consent form were explained to all parents and re-visited at different times during the interviews; thus, participants' autonomy was considered by providing the participants with the opportunity to make their decisions on participation based on the information that was given about the research (Biros, 2018). Moreover, parents were informed with an explanation that the withdrawal from the research would not be possible once the study has been published or the thesis has been submitted. Information on withdrawal from the study was also provided in the PIS.

4.8.1.1 Verbal consent

Autonomy was also reassured for parents who wished to be interviewed at another date or time through the telephone, though verbal consent was taken over the telephone before the interview in the Arabic language (appendix-IX). The verbal consent process for each telephone interview was audio-recorded, and transcribed. The verbal consent form consisted of the same points included in the written consent form. Prior to the telephone interviews, the researcher read through the verbal consent script and the verbal consent points, and the parent was asked to provide the responses to each point by saying "Yes" or "No". Last, the researcher asked the parents if, after they had given their responses to the earlier stated points, they agree on participation with a

"Yes" or "No" answer. Once, the response of the parent was obtained, and any questions or information requests were addressed, the researcher started to conduct the interview.

4.8.2 Confidentiality and Anonymity

In qualitative research, the researcher should respect the participants' privacy by reassuring anonymity and confidentiality (Creswell and Poth, 2018). The participants were informed that some quotations of their transcribed interview would be shared in publications and my PhD thesis with their names removed so the reader could not recognise them.

Privacy and confidentiality were confirmed during the face-to-face interviews for both children and their parents in separate individual interviews by conducting the interviews in a private classroom at the Cardiology OPC at the hospital. The classroom was booked in advance with the permission of the OPC's head-nurse to allow sufficient time for each child-parent dyad (1-2 hours/dyad). Privacy and minimum interruptions were ensured by keeping the classroom door closed during the interview. For the telephone interviews, confidentiality was ensured by using a mobile phone that is kept for research purposes only, and by conducting the interview in a private room where the participants' voices could not be overheard.

In terms of data protection and storage, data from this study are kept anonymised and confidential according to the University of Leeds guidance for good research practice and the Data Protection Act. The researcher assured the participants that their names would be removed from the interview transcript, audio-recorder, field notes, and memos and were replaced with pseudonyms known only to the researcher and stored in the UOL M-Drive for three years after completion of data collection. All families' contact numbers are stored on the UOL M-Drive, which is accessible only to the researcher. The numbers are also stored on a sim-card of a mobile phone that was used

explicitly for research purposes only. The mobile phone was used to contact the participants/potential participants and record the interviews. The mobile was secured with a password that is known only to the researcher. The researcher destroyed the sim-card after completion of data collection and will delete the contact numbers from the M-drive at the end of the research when the summary of the research results has been sent to the participants.

Moreover, in this research, as a back-up, a digital audio-recorder was used as well as the mobile recorder. However, the recordings were only uploaded from the mobile recorder, and there was no occasion where the researcher needed to use the backed-up recordings from the digital recorder. Thus, all recorded data were deleted from the digital recorder, and all recordings from the mobile were stored in the UOL M-Drive.

4.8.3   Ethics for researching with children

4.8.3.1   Child's assent

As children were invited to take part in this research and to speak for themselves, it was crucial to consider the possible ethical issues and challenges related to dealing with children. Children as participants have to be informed about the research process so they can choose whether or not to participate, withdraw at any time, know about possible harm and benefits, and the presence of any limits to confidentiality prior to enrolment in the research (Shaw et al., 2011).

Each child's agreement and assent to participate in the research was attained before the interviews. Although children's assent provides them with the chance to express their willingness to participate in research, it is recommended to keep it personalised according to the child's capacity (Waligora et al., 2014). According to the guidelines for researching with children and young people, young children, who are under 16 years old, need parental agreement before they participate in research (Shaw et al., 2011).

Therefore, in this study, which involves 4 to 10-year-olds, consent was taken from the parents first and included in their informed consent form (appendix-VIII), followed by taking the child's assent, to avoid situations where parental refusal is identified after taking a child's agreement to participate (Shaw et al., 2011).

In this study, all children provided their assent with the help of their parent, where the points were read to the child and the child responded by drawing a circle around the word "Yes" or "No" next to each point (appendix-X). For children who were younger than six years old, and/or had difficulty in reading, the points in the assent form were read to them by the parents. Moreover, during the interview, the researcher regularly checked the willingness of the child to continue participating, as the child might find it hard to tell the researcher that they wish to stop the interview (O'Reilly and Dogra, 2016). Hence, there were some occasions where children expressed the wish to discontinue the interview by acting bored or asking to stop and wanting to go home. In these cases, the researcher tried to entertain the child using drawings, or take 1-5 min break and, then, responding to the child's wish to stop or resume the interview.

4.8.3.2 Child's anonymity and confidentiality

The principle of anonymity in researching with children aims to protect the children from potential harm and even enhances the level of their honesty during the interview (O'Reilly et al., 2012). Thus, following the guidelines for research with children and young people provided by Shaw et al. (2011), children were assured that the information given during the interview would not be shared with other participants, parents, or others. However, in the children's interviews, the anonymity should be limited in case of any signs of injury, disease, or abuse detected. In this case, the researcher should break the confidentiality agreement by informing relevant professionals, and the children and their parents were informed about the limits of confidentiality

prior to their study enrolment (Shaw et al., 2011). However, in this study, there was no detection of such cases of abuse or injuries, and no breaking of confidentiality was required. All anonymity, confidentiality, and data protection procedures explained earlier were applied equally with parents and children.

4.8.3.3 Child's protection from harm and distress

With special attention to young and ill children, parents might be concerned about their children's safety (Fargas-Malet et al., 2010). In this study, it was possible that the children may become upset or traumatized by reflecting on their health and experiences of healthcare and this was minimized by conducting the interviews at a time and place that was convenient to the child and parents. Also, the children were reassured that they do not have to answer any question which made them feel uncomfortable, and that they could take a break at any time during the interview. Moreover, the option for the parents to be present during their children's interviews was provided to minimize any uncomfortable feeling the parents or the child might have.

Deciding on parents' presence during the child interview was a crucial consideration in this research where young children were involved. Children can feel shy or hesitant to talk in front of their parents about their feelings or other sensitive information (O'Reilly and Dogra, 2016). The presence of parents during the interview may reassure the parents that they are around their children if they felt discomfort or are worried, but could impede the child from speaking freely in the presence of their parents. Nevertheless, if the child presented with special needs or disabilities, or the child requested their parent's presence, the researcher should respond by allowing the parents to attend their child's interview (Shaw et al., 2011). However, in this study, no child with special needs was identified, and the researcher discussed with the parents the reasons why, if at all possible, it was preferable to interview the

child alone. Moreover, the wishes of the child and parents regarding the parents' presence in the interviews were respected.

Most of the parents agreed to the researcher talking to their children alone, and they talked to their child about the option to do this. Nevertheless, the researcher responded to the child's wishes and ensured the parents were present during their children's interviews if the children preferred this option. No conflicts emerged from parents' presence at the interviews; only some parents attempted to answer instead of their children in order to try to help their children answer the questions. However, the researcher explained to the parents that it is important for the children to talk and clarify their points themselves, and the parents were very understanding and cooperative. It is difficult to be certain about the impact of parents' presence on the children's answers to the interview's questions, and whether or not they would withhold some valid answers from the researcher because of their parents' presence in the room (O'Reilly and Dogra, 2016); however, the decision for parents' presence was offered in the current study so that parents could decide on what was more comforting for their children. In reality, most of the parents let their children decide on their presence, and the researcher responded to their wishes.

Parental influence on children's responses was identified in a previous study by Lifland et al. (2018), which gathered parents' proxy reports and children's self-reports via online surveys about children's pain and quality of life after surgery. The study acknowledged that there was a possibility that some parents had influenced the responses of the children, or vice versa, and this had impacted on the study's findings (Lifland et al., 2018). To avoid such conflict and to ensure that children's voices were sought and heard, the researcher in the current study checked that parents understood the value of their children's views and avoided interfering with their responses to the interview questions.

4.9 The quality of the constructivist Grounded Theory study

According to Morse et al. (2002), rigour in qualitative research is vital to the significance of the study and contribution of knowledge. To verify the rigour and accuracy of the data collection, interpretations, and reporting, guidelines provided by Charmaz (2014) on ensuring the quality of the constructivist GT were followed, which suggest ensuring credibility, originality, resonance, and usefulness (Charmaz and Thornberg, 2020).

Credibility was maintained throughout this study by ensuring that participants' views were faithfully transcribed, described and interpreted (Sandelowski, 1986). The researcher made sure to stay sensitive to the experiences and views shared by the children and their parents to enable clear and true representations of their perceptions. Writing memos and diagramming of data obtained from participants throughout the analysis process, aided the researcher to maintain credibility. Moreover, peer debriefing is another method which the researcher used to ensure credibility by discussing methodology, data analysis and interpretations with the supervisors who have expertise in qualitative research (Hadi and Closs, 2016; Lincoln and Guba, 1985). This debriefing evoked deep analytical thoughts and enhanced criticality in data interpretation, which helped the researcher to ensure that the interpretations were grounded in the data with reasonable links and relationships (Long and Johnson, 2000). Also, in constructivist GT, the credibility includes involving the researcher's views in interpreting the data (Charmaz and Thornberg, 2020; Charmaz, 2017), which was also achieved by the researcher's interpretations in analysing data and developing a theory. Furthermore, following the criteria of enhancing credibility in constructing GT as suggested by Charmaz (2014), the researcher made sure to find strong links and relationships between the emergent categories and provided evidence from existing literature that supported the researcher's interpretations and the proposed theory.

Originality can be confirmed by the contribution of new knowledge from the study, and the provision of new insights about a phenomenon (Charmaz and Thornberg, 2020). Coherent with constructivist GT quality criteria, the researcher undertook a study that has originality in that it provides fresh knowledge about the relationships between CHD related stressors and children's behaviour and emotions in Saudi Arabia.

Resonance indicates that the generated knowledge represents research participants' experiences and can offer rich understandings of their lived circumstances (Charmaz, 2014; Charmaz and Thornberg, 2020). Accordingly, to maintain resonance and representation of children's and parents' perceptions, the researcher in this study ensured that the emergent theory matched the description of the participants, and provided a deep understanding to the families and health care providers about the children's behaviour and emotions when having CHD.

The usefulness of constructing a GT involves offering improvement, new implications and a contribution for future practice and knowledge (Charmaz and Thornberg, 2020), and that it can suggest the application of the emergent theory in another setting (Charmaz, 2014). The researcher ensured that the analysis and findings of this study generated a theory that can aid healthcare providers and families of children with CHD to understand the behaviour and emotions of children with CHD in SA and, thus, improve the care provision. The findings of this study also suggested testing the application of the emergent theory in another substantive area.

4.10 Summary

This chapter presented the procedures and methods which this study adopted. The process of participant identification, and recruitment were first elaborated. Following the guidance of Charmaz on conducting a constructivist GT, the researcher planned two sampling procedures, purposive and theoretical sampling, respectively. The data were obtained from parents and children, mainly through face-to-face, in-depth, and semi-structural interviews. Some parents were interviewed by the telephone according to their stated preferences. For children's interviews, an Arts-Based approach was used to facilitate children's engagement. Then, the data analysis process was described following the procedures of coding, constant comparison, and memo writing. Data analysis and data collection were conducted concurrently, so ensuring the process was consistent with the iterative process of GT methodology. Ethical considerations for conducting this research were also explained. Procedures of informed consent, confidentiality, and anonymity were described. Moreover, special ethical considerations for researching with children were acknowledged and discussed. Finally, the rigour and quality entailed in conducting this constructivist GT were discussed.

The next chapter presents an overview of this study's findings, characteristics of the participants, and the generated categories.

Chapter 5 Findings overview

5.1 Introduction

This and the following four chapters present the findings of this study. Initially, this chapter presents participants' demographic information, descriptions of interviews followed by an overview of the emergent categories and the core category. The next four chapters present the findings under each sub-category. The theory development process is presented later in chapter 10.

5.2 Characteristics of the participants

The total number of participants was 20 (10 families, or child/parent dyads). Of the 20, seven boys and three girls with CHD, and six mothers and four fathers participated. There were two children aged 4 years, one aged 5, three aged 6, two aged 8, one aged 9, and one aged 10 years old (Table 5.1).

The ten families were identified using two sampling strategies (see Chapter 4). The first sampling strategy was purposive sampling, in which an initial sample of eight families was obtained. Out of the eight families, five male and three female children, with an equal distribution of CHD severity among them were interviewed. Of the eight children, five mothers, and three fathers were interviewed in this purposive sampling phase.

Following purposive sampling was theoretical sampling, in which a further two families were sampled based on the concepts and categories that were generated from the analysis of data gained from the initial sample. In theoretical sampling a heterogeneous sample of more female children, children with mild CHD or in the pre-operative stage of treatment, and fathers of children with CHD were targeted. However, the main focus at this stage was to validate the generated themes and categories, which was accomplished by modifying and adding relevant questions in the interviews (See Appendix-V). When recruitment started in the theoretical sampling phase, more male

children were identified as eligible participants than female children. Thus, the two families interviewed at this sampling stage were families of male children, of whom one had a mild case of CHD. Of the two male children, one mother and one father were interviewed. A summary of the sampling process is demonstrated in figure 5.1. Further information about participant identification and recruitment is available in Table 5.1.

Five of the children were diagnosed with severe CHD including tetralogy of Fallot (TOF), coarctation of the aorta, transposition of the great arteries (TGA), and double inlet left ventricle (DILV). The other five children were diagnosed with mild to moderate CHD including ventricular septal defect (VSD), atrial septal defect (ASD), left ventricular outflow tract (LVOT), pulmonary atresia (PA), and cardiomyopathy. The children had undergone different types of interventions for repair. Seven of the ten children had undergone one or two cardiac interventions, surgical and cardiac catheterization interventions. Moreover, the participants' families (children and parents) were from a range of neighbouring Arab nationalities. All families from all nationalities lived in SA at the time of the study. Further information about the participants' characteristics is available in Table 5.2. Pseudonyms were given for all children and their parents to protect their identification and ensure privacy in Table 5.3.

Table 5. 1: Participants' identification and recruitment table

Date of identifying families	Identified/ approached families	Dates of the child's appointment	Recruited families	Interviewed families
Recruitment following purposive sampling: Eight families				
1st week: 07/10/2018	5 families identified: 1. Female, 4 years old with mild CHD 2. Male, 6 years old with severe CHD 3. Male, 6 years old with mild CHD 4. Female, 6 years old with mild CHD 5. Male, 7 years old with mild CHD Families (1 and 5) did not respond to follow up messages	08/10/2019	Families (2 and 3) agreed to participate	**Two families were contacted for their interviews**
2nd week: 22/10/2018	6 families were identified: 1. Female, 8 years old with severe CHD 2. Male, 10 years old with mild CHD 3. Male, 4 years old with severe CHD 4. Female, 6 years old with severe CHD 5. Female, 6 years old with CHD	22/10/2018 & 23/10/2018	Families (1 and 4) agreed to participate	**Two families were contacted for their interviews**
3rd week: 29/10/2018	6 families were identified: 1. Male, 9 years old with mild CHD 2. Male, 8 years old with mild CHD 3. Female, 8 years old with severe CHD 4. Male, 5 years old with mild CHD 5. Male, 6 years old with mild CHD 6. Female, 4 years old with severe CHD	29/10/2018	Family (2) was recruited and agreed to participate	**The one family was contacted for their interviews**
4th week: 18/02/2019	1 family was identified: 1. Female 5 years old with mild CHD The family refused to participate	25/02/2019	--	--
5th week: 25/02/2019	2 families were identified: 1. Female, 4 years old with severe CHD 2. Male, 10 years old with mild CHD Family 1 refused to participate	05/03/2019	Family 2 agreed to participate	**The child was interviewed on the same day, and the mother through the telephone**
6th week: 05/03/2019	2 families were identified: 1. Female, 5 years old with mild CHD 2. Male, 4 years old with severe CHD	11/03/2019	Both families have agreed to participate	**The two families were interviewed on the same day of their child's appointment**
7th week: 11/03/2019	4 families were identified: 1. Male, 5 years old with mild CHD 2. Male, 6 years old with severe CHD 3. Female, 8 years old with mild CHD 4. Male, 4 years old with severe CHD	18/03/2019	--	--

Date of identifying families	Identified/ approached families	Dates of the child's appointment	Recruited families	Interviewed families
	All families refused to participate			
Recruitment following theoretical sampling				
8th week: 25/06/2019	2 families were identified: 1. Male, 4 years old with severe CHD 2. Female, 10 years old with severe CHD Family 2 refused to participate	30/06/2019 And 02/07/2019	Family 1 asked for future appointment for the interviews - The family did not respond to follow up messages	--
9th week: 02/07/2019	2 families were identified: 1. Male, 4 years old with mild CHD 2. Female, 7 years old with severe CHD Both families refused to participate	09/07/2019 And 11/07/2019	--	--
10th week: 09/07/2019	1 family was identified: 1. Female, 9 years old with mild CHD The family did not respond to the message and did not show up on the child's appointment date	14/07/2019	--	--
11th week: 14/07/2019	3 families were identified: All families of male children, 4 years old, one is pre-operative and the other two are post-operative. - Family 1 and 2 did not respond and did not show on the their appointments day	23/07/2019	-Family 3 responded and agreed to participate	**The child was interviewed on the day of the appointment, and the mother was interviewed a week later on the telephone**
12th week: 23/07/2019	1 family was identified: 1. Male, 7 years old with severe CHD	30/07/2019	The family did not respond to the message. However, on the day of their appointment agreed to participate	**The child was interviewed on the same day of the appointment. The father's was interviewed on the telephone a month later**

Figure 5. 1: Sampling process

Purposive sampling (initial sample) (n= 8, child and parent dyads)	
Child: 4- 10 years old with CHD. Male and female with any type of CHD, who had undergone any type of treatments	Parents: Parents of all eligible children

Analysis of initial data:
Coding and generated initial categories

Theoritical sampling (n=2, additional child and parent dyads)	
Adding population: more fathers, female patients, 7 and 9 years olds, and pre-surgical patients or less invasive procedure (eg. catheterization)	Modifying interview questions

Table 5. 2: Participants' characteristics

Families / Criteria		1	2	3	4	5	6	7	8	9	10
Age in years	4								√	√ (4 and half)	
	5							√			
	6	√		√	√						
	7										
	8		√			√					
	9									√ (according to dad)	
	10						√				
Birth order		1st	2nd Twin	3rd	1st	2nd	1st	4th youngest	1st	4th youngest	1st
Severity / Diagnosis	Mild- Moderate (a cyanotic)	VSD	VSD +ASD	__	__	__	LVOT	Pulmonary artery atresia	__	Cardiomyopathy (and left ventricular dilatation)	__
	Severe (cyanotic)	__	__	TOF	TOF	TOF	__	__	CO-Aorta, TGA, DILV	___	TOF
	Age at time of diagnosis	After birth	8-9 months	1 month	9 months	After birth	Post birth	3 months	40 days	40 days	After birth
Intervention	Surgery- (Post/pre)	Post	Post X2	Post	Post x2	Post	Monitoring (follow ups)	Monitoring (follow ups)	Post waiting 2nd OR	Monitoring -on medications (Follow ups)	Post
	Catheter (Post/pre)	__	__	__	Post x3	Post x2			__		__

Families / Criteria		1	2	3	4	5	6	7	8	9	10
	Age at time of treatment	2 years	9 months	2.5 months	2 years	>3 years			3 months		8 months
Gender	Male	√	√	√			√		√	√	√
	Female				√	√		√			
Parents	Mother	√	√				√	√	√	√	
	Father			√	√	√					√
Country of birth		Saudi Arabia (SA)	SA	SA	Other Arab Country (OAC)	OAC	SA	SA	SA	SA	SA
Country of diagnosis		SA	SA	SA	OAC	OAC	SA	SA	SA	SA	SA

Table 5. 3: Participants' pseudonyms

Families	Children	Parent
Pseudonyms		
Family 1	**Mohammed** (Boy 6 years old)	**Mariam** (Mother)
Family 2	**Fahad** (Boy 8 years old)	**Farah** (Mother)
Family 3	**Hadi** (Boy 6 years old)	**Hilal** (Father)
Family 4	**Leen** (Girl 6 years old)	**Latif** (Father)
Family 5	**Sara** (Girl 8 years old)	**Salim** (Father)
Family 6	**Kamal** (Boy 10 years old)	**Kamela** (Mother)
Family 7	**Kadi** (Girl 5 years old)	**Hana** (Mother)
Family 8	**Adil** (Boy 4 years old)	**Aida** (Mother)
Family 9	**Maher** (Boy 4 years old)	**Maha** (Mother)
Family 10	**Ali** (Boy 9 years old)	**Ahmed** (Father)

5.3 Process of generating categories

The process of generating the categories started from the initial data collected as guided by Charmaz (2014). The summarized process of generating sub-categories and core category is provided in figure 5.2. First, reading and re-reading of transcripts assisted the familiarisation with the data and the initial coding process. The initially generated codes were (n=25) that were grouped under (n=7) categories. An example of an initial coding sheet in a Word document is provided in appendix-VI. Then, the focused coding process

started with writing memos and diagramming. The constant comparative analysis was followed throughout all stages of data collection and analysis process, which helped in generating initial categories. Afterwards, theoretical sampling was followed and theoretical codes were generated. The codes and coding stages are summarized in Table 5.5. Before the identification of the core category, three sub-categories, and four influencing factors (Table 5.4), in-depth analysis, sorting memos and self-immersing in the data, several versions of diagrams, and tables were used to conceptualize connections and links (appendix-VII); finally, the final versions of the generated categories were achieved (Figure 5.3). Chapter 4 presented more description of how memos and diagrams were prepared. The researcher integrated her personal knowledge and experiences about child health nursing when analysing and emerging the concepts and categories based on children's and parents' views. However, by constantly comparing the generated codes and categories with the participant's verbatim transcripts, the researcher made sure that her interpretation during the analysis process truly emerged from the data. Further description of the quality of the current study was provided in section 4.9 in Chapter 4.

Table 5. 4: The core category, sub-categories, related concepts, and influencing factors

Core category	Sub-Categories	Properties/ concepts of sub-categories
Behavioural and emotional reactions to stressful life events related to living with CHD	1. CHD medical treatment stressors	• CHD correcting procedures • Hospital admissions and visits
	2. Sociocultural stressors	• Family relationships • Schooling • Friendships • Sharing news with others
	3. Physical changes stressors	• Physical activity limitation • Presence of scar from heart surgery
	Factors influencing the sub-categories:	
	• Child's awareness of CHD • Parenting • Child's speech and recall issues • Family's immigration	

Figure 5. 2: Process of generating categories

Familiarazation with data
Initial coding
Memos and diagramming
Focused coding
Conceptualizing
Initial categories
Memos and diagramming
Theoretical sampling
Theoretical coding
Sorting memos and diagrams
Conceptualisation of initial categories
Core category + Sub-categories

Compare and contrast (constant comparison)
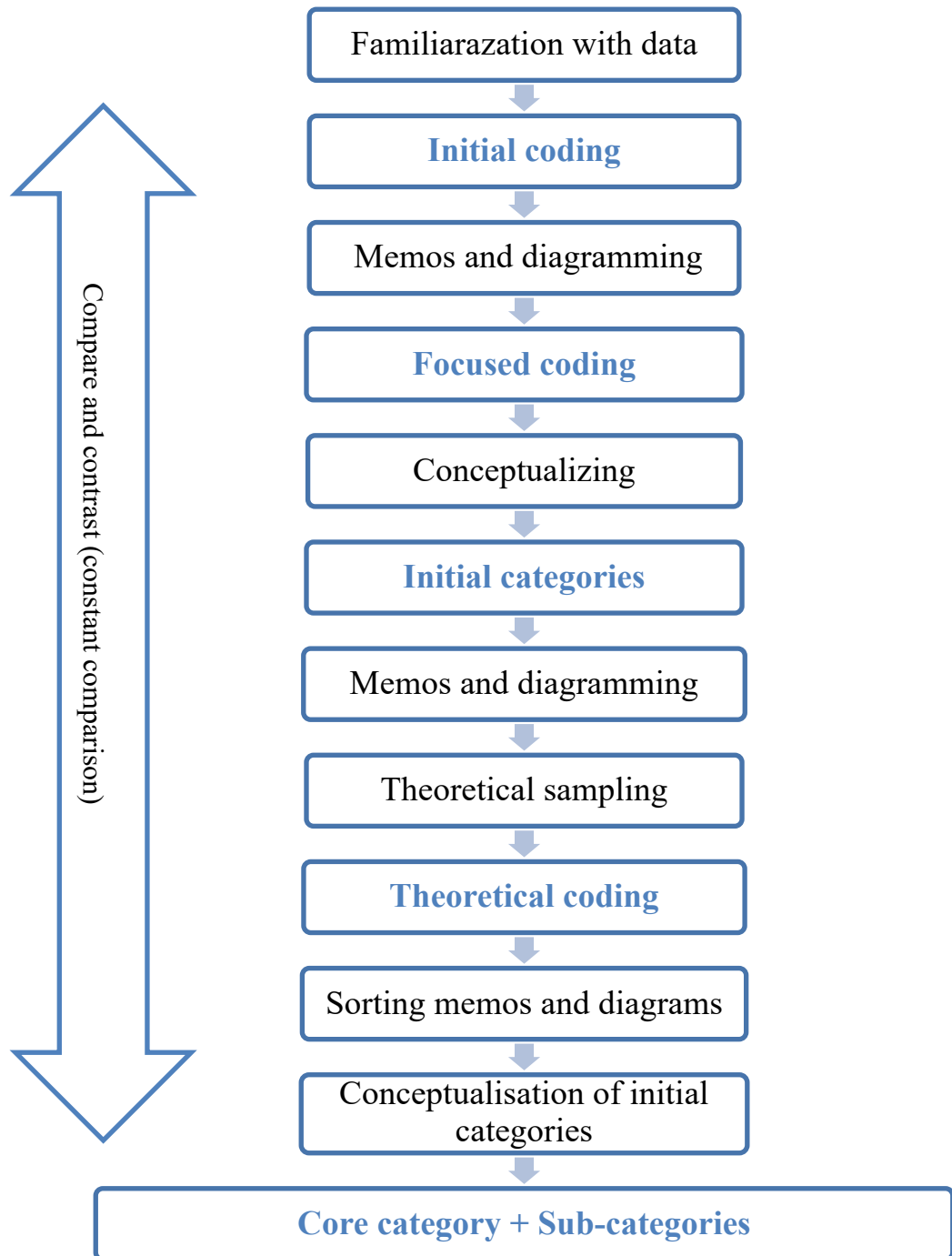
Table 5. 5: Coding stages

Interview topics	Initial coding	Focused coding	Theoretical coding
• Child's feeling toward self and heart condition awareness • Child's self-perception of behaviour and emotions • Parents' perception on children's behaviour and emotions • School activities and socialisation • Parent's knowledge about their children's condition • Coping and support	Child's behaviours: • Fighting / Easily cries and stubborn • Changes overtime • Soft hearted /caring • Special attention/ seeking attention -Child's emotions: • Feeling towards CHD: treatments/ hospital visits • Expressing emotions : anger / sad /upset • War and immigration -Child's social relationships: • Siblings • Child-parents bond/ Parental discipline: special treatments, and guilt feeling • Friendships • Loss of loved ones -Child's adjustment and coping to live with CHD: • Sharing news of CHD condition / Denying CHD • Friends of other children with CHD /Support group • life changes -Child's awareness of CHD condition: • Unaware children/ Parental protection • Aware children • Doctors' role/ Parental knowledge role -Learning and speech difficulties -CHD symptoms and physical activities • Activity level • Post-surgical scar / Comparing self to healthy friends	-Child's awareness of CHD • Aware child • Unaware child • Parents protection: Influences on awareness - Feeling towards CHD: • Going through treatment • Hospitalisations -Sociocultural pressure: • Sharing experiences with others • Siblings • Parental bond/ Parental discipline • Friendships • Loss of loved ones - CHD symptoms: • Activity level/ play • Self- comparisons with other healthy peers • Post-surgical scar -Schooling and learning: • Recall and speech difficulties • Delay in schooling -Changes in life circumstances: • War and immigration • Delay in treatment	- CHD treatment: • Awareness of CHD • Treatments/ hospitalisation • Delayed medical care -Sociocultural: • Sharing experience of CHD • Family relationships • Parenting • Friends • Schooling -Physical symptoms Changes: • Activity level and play • Chest scar -Other factors: • Family immigration • Learning, recall and speech difficulties

Figure 5. 3: Relationships between core category, sub-categories, and influencing factors
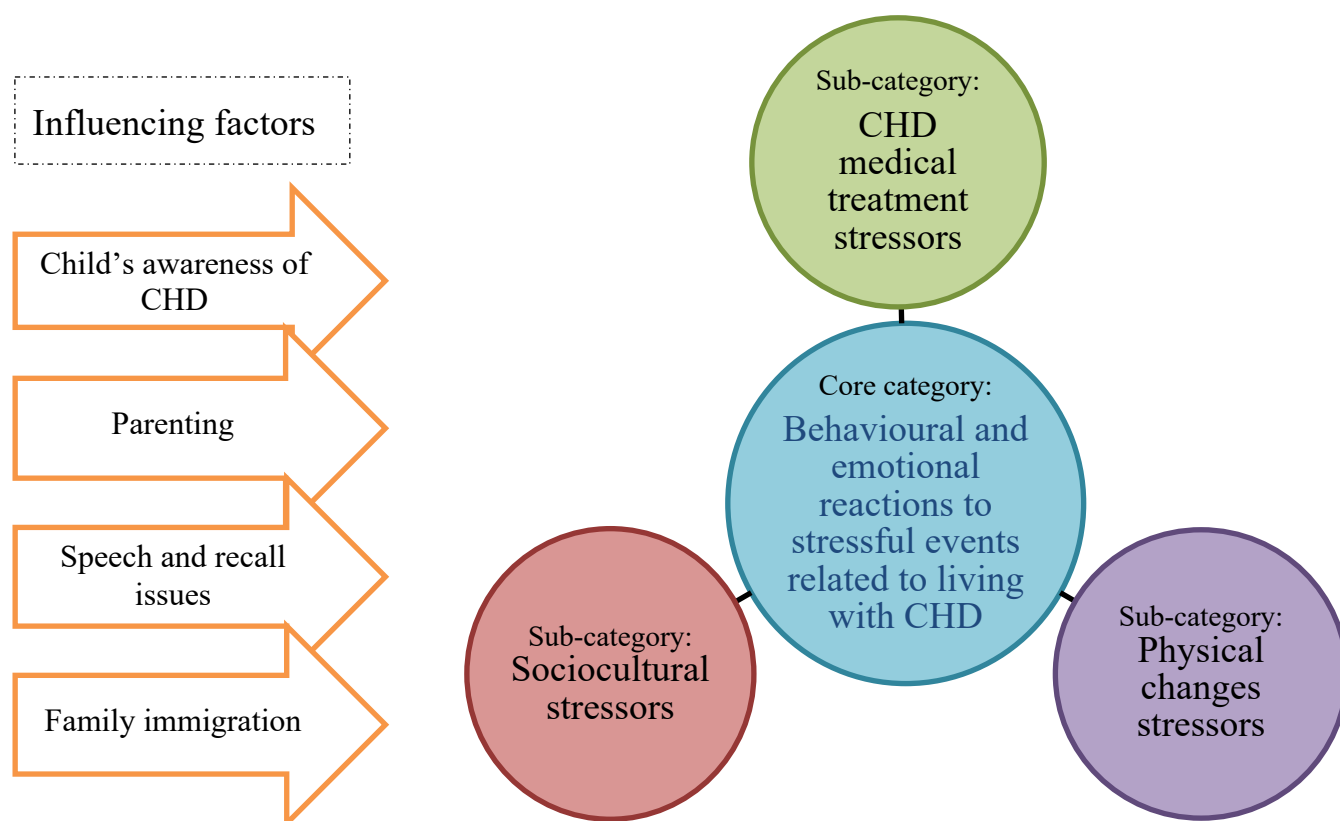
5.4 Overview of core category, sub-categories, and influencing factors

The main concern and core category for children with CHD in this study was *the behavioural and emotional reactions to stressful events related to living with CHD*. Based on the experiences reported by children and parents, and the interpretation of the researcher, this core category was identified. Children showed different behavioural and emotional changes in response to stressful events that were related to the CHD condition. Based on the researcher's interpretation of these stressful events, they were then called stressors, as they were found to affect the children's behaviour and emotions while living with CHD. Stressors are identified as the factors which a person can face from any

life changes including possible challenges, burden, harm or pressure (Wheaton and Montazer, 2010). For example, managing stress when dealing with the treatments and hospitalisations related to CHD, pressure from family and social interactions, and physical changes associated with CHD. These stressors are identified as sub-categories for the children to react behaviourally and emotionally. The sub-categories are *CHD medical treatment stressors, sociocultural stressors, physical changes stressors*. Furthermore, several factors were found to influence children's reactions to the stressors (influencing the sub-categories). Child's awareness of CHD was found one of the significant influences on children with CHD. Their awareness influenced the way the children responded and reacted to the identified stressors. Parenting also played an important role in child's awareness and their behavioural and emotional reactions towards all three stressors. Moreover, some children were having speech and recall difficulties or issues which contributed to the way they faced the stressors. Family immigration status was the fourth factor influencing the child's experience with CHD treatment and the related stressors and thus the child had behavioural and emotional reactions accordingly. Figure 5.3 presents an overview of the relationships between the categories and the influencing factors.

5.5 Summary

This chapter presents the characteristics of the participants, and an overview description of the participants and the interviews. The process of generating a core category, sub-categories and influencing factors was also provided. Figures and tables were presented to summarize the steps and stages of coding, and the emerged categories. Finally, an overview description of the categories and influencing factors was provided. Further illustration of the sub-categories, influencing factors and the related findings are presented in the next chapters, which provide supportive evidence for *the behavioural and emotional reactions to stressful events related to living with CHD* as the core category.

Chapter 6

Sub-category: CHD medical treatment stressors

6.1   Introduction

This chapter presents the findings of the first sub-category, which explains how children's treatment of CHD, the different severities and types of management, could lead to their emotional and behavioural reactions. Children experienced different emotional and behavioural reactions while going through cardiac surgery and/or catheterisations, hospital admissions, or hospital visits, which are also described here as concepts of this sub-category (Figure 6.1). Therefore, this chapter reports children's self-reports and whether their parents' proxy reports provided support for or opposition to what their children self-perceived.

Figure 6. 1: Concepts of sub-category: CHD medical treatment stressors
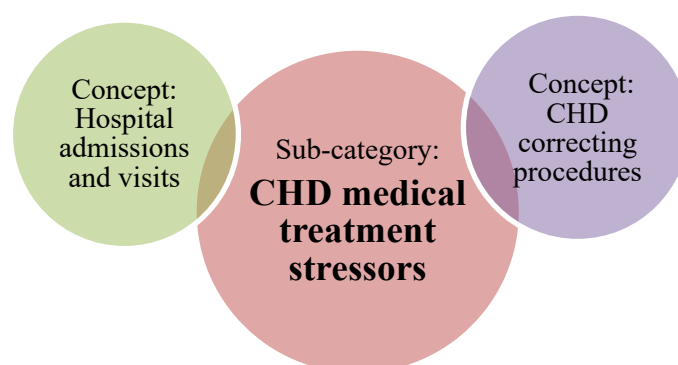
6.2   CHD correction procedures

Children had undergone invasive procedures as part of the management and corrections of their CHD; these were either cardiac surgery, or catheterization, or both. Some children had severe cases of CHD for which they had undergone both invasive procedures, surgery and catheterization, for CHD repair. Cardiac catheterization was performed for some children as a diagnostic procedure for CHD or for repair of the defects. Only two of the children (a boy and a girl) had not undergone invasive procedures in their plans for CHD management; instead, they were on regular medication and hospital follow-ups. On the other hand, two other girls had undergone multiple episodes of both surgeries and catheterisations, and one boy had undergone two surgeries. The rest of the children had undergone single surgery.

This section presents children's self-perceptions about going through the different CHD management and treatments, what they felt and how they behaved before the treatments and afterwards. Parents also reported on their children's emotions and behaviours before and after receiving the treatments. Both perceptions revealed stressful situations where children reacted behaviourally and emotionally towards them. In this section, the stressful situations for children were: undergoing CHD medical treatments, being admitted to the hospital to receive CHD correction procedures, and frequent hospital visits for follow up appointments.

Before receiving treatments, children described themselves as being sad and scared. The children used the facial emotions images (emojis) that the researcher shared with them to choose which face best described their feelings. Despite the very young age (< 3years old) of all the children at the time of their surgeries, they reported how they felt before and after the treatments. They commonly described how *"Sad"* and *"Scared and tired"* they felt before the surgeries, as opposed to them being happy and not scared after the surgeries. For example, Fahad who had undergone two surgical operations,

described his feelings before the operations, as being *"Sad and scared"* *(Fahad- child).* When the researcher asked about his feeling after the surgeries, he chose a happy emoji and reported himself as being *"not scared and not sad or anything"*, and *"A happy boy"* (Fahad-child).

Other children also reported that they felt happy when the surgical correction of their CHD was done. Hadi, on the other hand, described being happy before his surgery and reported not feeling anything after the surgery.

> *" I was happy when they did that [the heart surgery]" (Hadi-child)*

> *"I don't feel myself different [after the heart surgery]" (Hadi-child)*

Furthermore, Leen, a six year old girl, who had undergone two surgeries, and three cardiac catheterizations at two years old, also reported that she was happier after her surgeries than before. Leen drew a picture of herself and her heart and the researcher encouraged her to talk about how she felt. She talked openly about her heart condition. As she was drawing her heart (picture 6.1), she pointed at her heart and the heart surgery she had undergone. While pointing at her chest, she stated:

> *"They did a surgery for me, yesterday [she meant in the past]" (Leen- child)*

Picture 6. 1: Child's drawing (Leen)
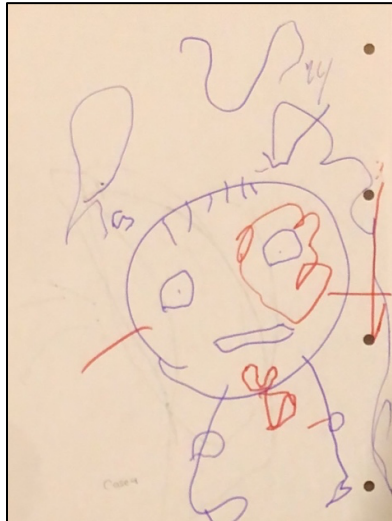
Sara, an eight year old, was another girl who had undergone both surgical and catheterization management, which were done after the age of three years old. She described the event when she was taken to the hospital in an ambulance. Then, she explained the setting and situation of the operation room while her parents were outside during the operation.

> *"They took me to the ambulance, and I was sick and tired and*
> *[unclear word]… I was tired, and I was sitting on the bed they put*
> *a [unclear word]… mom was outside, and dad was outside and I*
> *was inside the operation, and they did the surgery" (Sara- child)*

> *"I was feeling tired and sick and I went to the bed and I slept…*
> *and they said I have to take a medicine" (Sara- child)*

She followed this description with her immediate feeling after the surgery as being *"sick and tired" (Sara- child)*. During the interview, she was excited to use the pictures and colours that the researcher provided for her. She chose a pink heart and a happy face to describe her feelings and how her heart looked before the surgery.

> *"My heart .. dark pink [pointing at pictures of a pink heart]"*
> *(Sara-child)*

She also described how she felt immediately after the surgery:

> *Sara- child" Thank god" [pointing at a happy emoji]*

> *The researcher: and what does this face mean?*

> *Sara- child: "means fine"*

> *The researcher: you felt fine after the surgery?*

> *Sara- child: because I was tired and sick [before the surgery]*

Sara and Leen were two of the children who had delays in receiving their treatment due to their families' immigration to SA. Moreover, they both had speech or pronunciation issues, which made it challenging for the researcher to understand some words during the interview. However, with further explanation and probing questions, the researcher was able to follow their discussions. Findings related to family immigration and speech issues are presented next in Chapter 9.

Parents proxy reports were obtained on what they had noticed about their children's behaviour and emotions in relation to CHD receiving treatments. Commonly, parents noticed an improvement in their children's behaviour and emotions after the CHD correcting procedures and over time. For example, Latif, Leen's father, described his daughter as getting angry and easily crying before the surgery, which started to improve after the second surgery.

> *"Before the first operation, she was very young, and things was*
> *not obvious.. she just used to be very angry and sometimes she*
> *would wake up at night and cry all the night and we can't*
> *sleep…but after the first surgery, you would feel that she got*

angry, and angry and angry and her lips become blue and her
hands and she would throw things over". (Latif- Leen's father)

".. it's even before this surgery [second surgery], she started to
change, and she started to behave more.. but mostly she started to
change after this surgery [second surgery]". (Latif- Leen's father)

6.3   Hospital admissions and visits

This section presents findings of the other concept of the sub-category *CHD medical treatment stressors*, which is about the perceptions of children's feelings and behaviours towards hospital admissions and regular hospital visits for their CHD follow up appointments. To start, the researcher, asked the children to draw a picture of their hospital and talk throughout their feelings towards the hospital. Moreover, the researcher showed the children pictures of a hospital and a doctor to help them express their feelings when seeing them.

Remarkably, children reported not being scared or distressed about hospitals visits even after they experienced surgeries and frequent hospital admissions.

"I don't get upset with the hospital" (Leen- child).

Parents also reported their children were not scared of seeing doctors. For example, Mariam reported:

"He doesn't get scared of them [doctors and nurses]" (Mariam-
Mohammed's mother)

In fact, for some children, seeing the doctor who had done their surgeries was the reason for them to be happy to visit the hospital. Children at the outpatient clinics usually spend more time with doctors than nurses or other healthcare professionals, which can explain why children talk only about doctors.

Kamal had a mild CHD with regular follow up hospital visits. He also described being happy when visiting the hospital and got to see his doctor and other people he knew at the hospital.

> *"I would be a little happy… Because I meet the doctor" … "I know half of the hospital" (Kamal- child)*

Moreover, Sara expressed her loving feeling for the doctor who did the surgery for her:

> *"The one who did the surgery to me"… "Because he is [the doctor] in my heart…inside my heart" (Sara- child)*

Although he was happy to see his doctor, Ali, who had undergone surgical treatment, initially reported that he was unsure about his feelings when visiting the hospital or meeting his doctor *"I don't know what to feel" (Ali-child).* However, when the researcher introduced the emojis to him, he picked a smiley face. Afterwards, he was able to identify his feelings. Ali reported he was happy to visit his doctor because the doctor treated his condition and that he would visit him if he became sick again.

> *Ali: "happy .. like this [pointing at a smiley face]"*
>
> *The researcher: you would be happy .. why would you be happy?*
>
> *Ali:" just like that.. because I saw the doctor… because he cures me. I might be sick, so I go to the doctor". (Ali- child)*

A *"doctor's house"* was an expression of the hospital offered by Maher, a four and a half year old boy. He demonstrated at some points that he was unsure of his feeling toward the *"doctor's house"* and doctors. Earlier in the interview, he reported being happy to visit the "doctor's house" and see the doctor, yet, later he said *"no, I don't like it [the hospital]" (Maher- child)*. It is important to note that this child was one of two youngest participants in this study,

which might be a reason for his confusion or inability to properly report his feelings. Likewise, Kadi was a five year old girl with mild CHD who reported that she did not like to go to the hospital and did not say the reason when the researcher asked her. However, she liked visiting and seeing her doctor.

Hospital admissions and staying in the hospital for several days was a concern for Kamal, who was on monitoring and follow up visits since birth. Prior to the interview, the doctor explained a possibility for him to undergo a surgical repair for CHD. When the researcher asked him about his feeling toward undergoing a surgery, he reported:

> *"I don't want an operation... Who wants to set on a bed for six days?" (Kamal- child).*

Parents' reports about their children's emotions and behaviours towards hospital visits were supporting their children's self-reports. As reported by parents, their children enjoyed the days of hospital visits and that they were only scared of needles or injections.

> *"He doesn't get scared.. he is happy when he goes there [to the hospital].. he only gets scared of injections". (Farah- Fahad's mother)*

> *"She doesn't get scared ... She is happy to go to the hospital"...*
> *"She is scared of needles and sometimes medications" (Hana-Kadi's mother)*

One mother reported that not only her son liked to visit the hospital and loved his doctor, he also wished to become one himself.

> *"He is in love with the hospital.. and he loves the doctors"... "He says when I get older, I will become a doctor .. he is very proud of his doctor" (Kamela- Kamal's mother)*

Reasons for children liking hospitals and doctors, as reported by parents, were related to their children looking forward to having a quality time with their parents without their siblings. Ali reported his happiness to go to the hospital *"because I went with dad to the hospital" (Ali- child)*, which was also consistent with his father's report about him. Ali had heart surgery when he was eight months old and his father noticed his son was happy to go out with him and not specifically because of hospital visits.

> *"No .. I didn't notice happiness or something [towards hospital]*
> *...It's just he will be going out with me and stuff like that".*
> *(Ahmed- Ali's father)*

Another father reported his child was excited on the morning of his appointment at the hospital and said to his brothers:

> *"I have got rid of you today" (Hilal- Hadi's father).*

Furthermore, another reason for some children's happy feeling when visiting hospital was to skip a school day, according to their parents. Children would be usually absent from the school on the day of their hospital appointments especially if they lived outside the city and had to travel early on the day or a day prior to the appointment date. For example, Mariam, mother of Mohammed, reported:

> *"He [her son] tells me I want to go to the hospital just because he*
> *doesn't want to go to school". (Mariam- Mohammed's mother)*

Other parents reported that their children's feelings and behaviour towards hospital visits changed over time. They reported that the children were scared of the hospital only when they were younger and soon after the surgery was done. Over time, the children became used to hospital visits and were no longer scared. The following parents described how the behaviour of getting

scared or being afraid of the hospital or seeing doctors diminished after a while, post-surgery:

> *"It is a matter of getting used to it.. after the first surgery she got used to it. She is unlike other kids who see any doctor and would be scared. She is used to it"* (Salim- Sara's father)

> *"It was [getting scared] only when he was younger. but not now. He used to cry…I feel that he is more towards the positive side"* (Maha- Maher's mother)

> *"…but currently I don't find him crying that much. I mean the more he gets older in age, the less of that feeling".* (Ahmed- Ali's father)

Children's lack of awareness of the condition was another explanation a father provided for his son regarding him being fine when visiting the hospital. According to Hilal, his son, who had undergone a surgical repair, did not know about his condition and felt fine when visited the hospital.

> *"I see him fine…Because he's not aware about whatever he had been through".* (Hilal- Hadi's father)

However, this was inconsistent with what his son, Hadi, self-perceived during his interview; he demonstrated an awareness of his heart surgery. More findings related to children's awareness of CHD are provided in Chapter 9.

A traumatic experience in the intensive care unit (ICU) was described by a father, where his daughter had undergone two heart surgeries and three catheterization procedures. The treatments were delayed until she was two years old because of the war situation in their country and the need for the family to immigrate to Saudi Arabia. This girl was admitted in the ICU at hospital (the study site) for seven days and, as reported by her father, she was

emotionally affected when she saw other young children in the ICU connected to tubes and devices. The following is the report of her father about the experience in the ICU.

> *"When we were in the intensive care unit.. sometimes we would*
> *take her out for a walk, she stayed there for seven days... So, when*
> *she saw the other kids very young and connected to tubes and*
> *things, she asked (Dad, what happened to them? All of them are*
> *sick? Like me?).. and I would tell her yes they are sick like you …*
> *yes, she used to say (don't show them to me).. and like that".*
> *(Latif- Leen's father)*

Yet, despite her emotional experience in the ICU, Leen perceived her feeling as happy to visit the hospital afterwards for follow-ups, as presented earlier. Her father's report was in agreement to her self-report. He mentioned her being strong and not easily crying.

> *"No, she doesn't cry [when visiting hospital].. no, I think she is*
> *very strong.. she doesn't cry unless there is something made her*
> *too much upset". (Latif- Leen's father)*

6.4 Summary

Children's self-perceptions and parents' proxy reports about children's feelings and behaviours towards the CHD treatments and hospital visits, were presented in this chapter. Children reacted differently towards the stress of dealing with CHD conditions through their emotions and behaviours. Children and parents were generally consistent in reporting children's emotions and behaviours towards their treatments and hospital visits. Generally, children felt happy after completing the CHD treatments, whereas they compared themselves as sick and tired before the treatments (heart surgery and catheterisation). Moreover, most of the children were happy and not scared to visit the hospital and doctors, even after experiencing surgeries and hospitalisation.

Chapter 7

Sub-category: Sociocultural stressors

7.1 Introduction

The second sub-category presents children's emotional and behavioural reactions toward stress that is interpreted from dealing with social interactions, and relationships such as family relationships and schooling, while living with their CHD. Also, for a child with CHD, friendships and siblings' relationships were sometimes found to be stressful and significant for their behavioural and emotional reactions. Moreover, some of the children experienced loss (death) of a family member. Schooling as well acted as a stressor which is about what children with CHD faced in schools while going through the CHD treatments, such as being absent on school days. This includes perceptions from children with CHD and their parents regarding the daily school life of the child with CHD (Figure 7.1). Arab cultural aspects are interrelated with the social interactions of the children. Some of the cultural aspects are presented with the findings in this chapter, while other cultural aspects are discussed later in chapter 11. This chapter focuses on these sociocultural aspects and perceptions from both children and parents.

Figure 7. 1: Concepts of sub-category: Sociocultural stressors
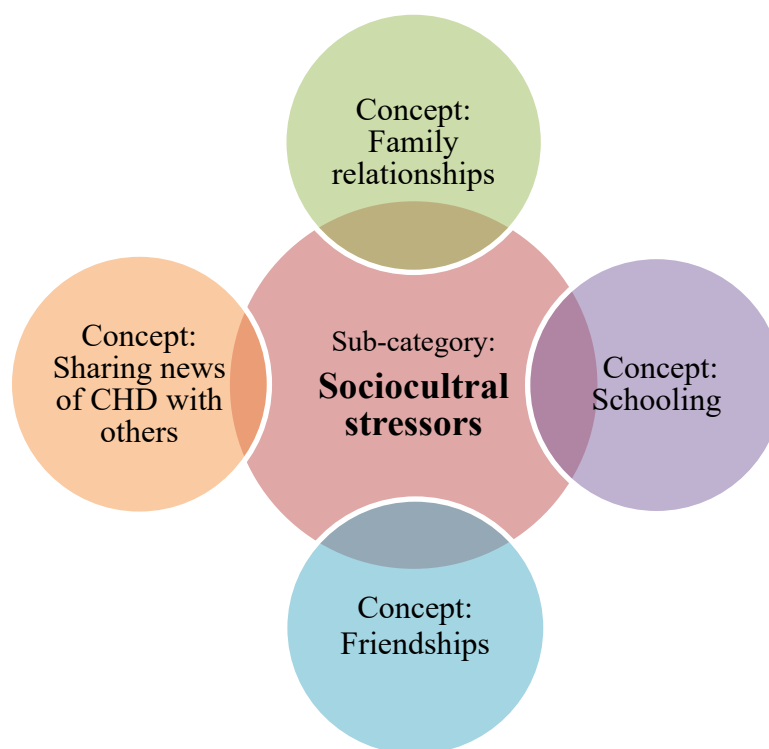
7.2 Family relationships

Children's relationships with parents and siblings were found to be significant to the behaviour and emotions of children when dealing with CHD conditions. Children reacted towards the stress of interacting with the family's social and cultural beliefs. Family's social and cultural beliefs were revealed in child-parent, and child- siblings relationships.

During the interviews, to encourage the children to talk about their families, the researcher asked them to draw their houses and talk about who lived in their house. Then, the researcher asked them to draw their parents and siblings while talking about the children's relationships with them. Subsequently, the children talked about how did they spent time with their family members. Emoji faces were also used to help children convey their feelings or behaviours.

Siblings relationships: Jealousy and caring

Relationships with siblings were reported to involve jealousy, preferential treatments, and competition. All children in their self-reports linked the feeling of being loved or unloved by siblings with how much they spent time playing together or how they fought with each other.

Brothers' and sisters' fights were commonly reported by most of the children. Hadi interpreted how much he felt unloved by the fact his brother and sister fought with him and did not play with him. However, when he was drawing his home and family, he drew his family members sitting together and playing on the left side of the picture and drew himself inside the house on the right side (see picture 7.1).

> *"They [brother and sister] upset me and fight with me.. they don't play with me… She [sister] doesn't love me.. I told her why? She said only [the older brother's name]". (Hadi- child)*

Picture 7. 1: Child's drawing (Hadi)
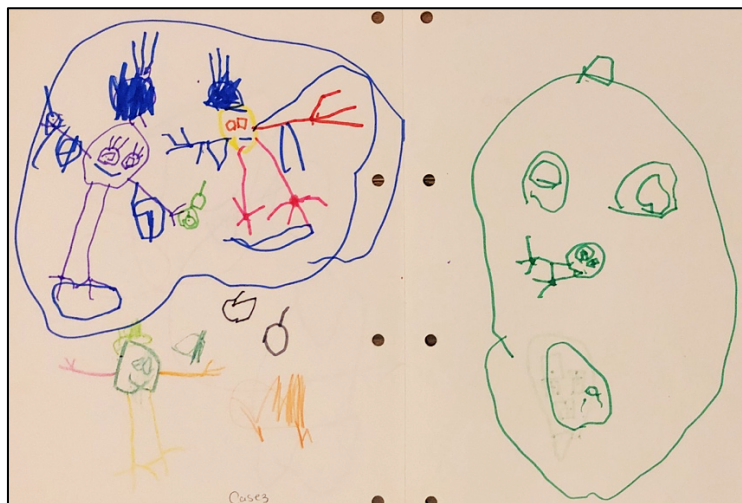
Moreover, Adil reported that he did not love his brother and sister because they fight with him, even though they were younger than him and his sister was one year old. This child also complained about friends fighting with him.

> *"They [brother and sister] always shout at me.. Every day he*
> *fights with me [brother]"(Adil- child)*

On the other hand, other children reported loving their siblings and related the feeling of love with spending time together in play. Children drew themselves and their houses and described what their houses and family looked like. In the picture below, Sara drew herself and her home next to it then described how much she loved her family (see picture 7.2). Ali, on the other hand did not wish to draw and talked straight away about his feelings towards his family.

Picture 7. 2: Child's drawing (Sara)
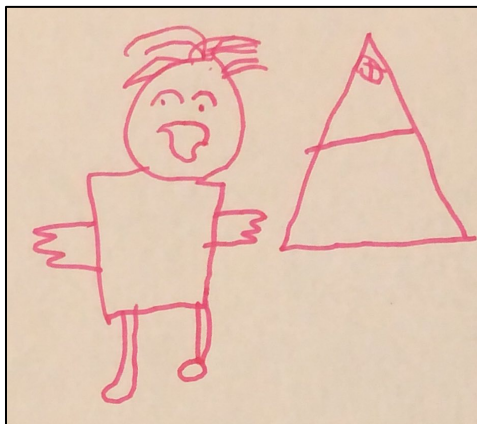
> *" I love my sisters.. with my heart ...They are my sisters they play*
> *with me every day, every day, every day" (Sara- child)*

> *"I like to play with my sister" (Ali- child)*

Furthermore, parents provided proxy reports on their children's relationships with their siblings. Jealousy was a significant feature in the relationship between siblings and the child with CHD. Parents reported many occasions where their children felt jealous of the sibling with CHD or vice versa.

Consequent to the jealousy, children compared themselves to other siblings and compared the amount of attention and love they received from parents and others.

Children with CHD felt jealous when their parents cared for the other siblings. As reported by parents, they did not want their parents to give away the care and love to someone else but them. One child felt his parents did not love him and told his parent that he *"want to die"* because he felt more attention was given to his older brother, as reported by his father. Yet, his father said that they (the parents) did not treat their children differently.

> *"He says he is lacking love or care like that.. he says [Hilal is quoting Hadi], (all of you don't love me.. I want to die) He feels like there is special care for the older one [older brother] and that he hasn't got the same attention". (Hilal- Hadi's father)*

A mother also described how much her son felt jealous of his sister, even though he received much more attention from parents than his sister did. She reported his attitude of wanting more care and attention and described him as *"not satisfied"* with what he had got.

> *"He gets jealous very much…He says [Kamela is quoting Kamal] (everything is for her [sister] everything is for her) but she doesn't get the half of what he gets.. yes he gets jealous. [Kamela is quoting Kamal], (no don't let her sleep next to you) he is not satisfied.. he is not satisfied with the things he has got.. He just wants to collect everything around him". (Kamela- Kamal's mother)*

Children felt jealous also of other children, other than siblings, who got care or attention from their parents. Parents talking to other children and complimenting them made Ali feel jealous. It is notable from the father's

report that this boy did not want to be perceived by his father as lesser of a good boy than any other kid.

> *"I find he sometimes doesn't like to see me.. to see me complementing anybody else.. If I would say that [his cousin] is a good boy, he won't like it .. he would say [Ahmed is quoting Ali], (no I am better than him)". (Ahmed- Ali's father)*

Despite the feeling of jealousy, most of the participating children with CHD were reported by their parents as caring and kind to their siblings. Caring or empathetic as some parent described, were the best qualities the parent saw in their children with CHD. Parents reported that their children got emotional when someone at home was sick and that they would take care of them and empathize with them.

> *"He is caring... When I get sick or anything you will find him the only one who cries for me when he sees me, he cries" (Farah- Fahad's mother)*

> *"She is the sweetest one. If one of her sisters is sick.. she will take care of her... The best quality of her is that she loves her sisters, if she finds one of her sisters crying she would cry with her. If she finds her sister sick she will take care of her". (Salim- Sara's father)*

Being caring and empathetic was also reported by other parents who described their children as passionate, caring to their parents, and helping around the house.

> *"He has a good heart. From the outside, you would find him angry and grumpy, but from the inside, you would feel that he is caring .. I mean he helps me around" (Aida- Adil's mother)*

"He has a soft heart.. he is generous ... He would always hug me
and he misses me [laughing] even if he listens to a romantic song
he dedicates them to me" (Kamela- Kamal's mother)

Ahmed also reported his son as being sensitive to his brother and wanting the best for him. Ahmed described how upset his son became when his father tried to fix his brother's hair, thinking that his brother did not look nice.

"... and he cried that time... I told him, what is it? He said [
Ahmed is quoting Ali], (you don't want my brother to look nice)
and I explained that your brother's hair was like that, but he
refused to listen to me .. he said[Ahmed is quoting Ali], (you want
people to laugh at him)" (Ahmed- Ali's father)

Child-Parent bond

Children with CHD exhibited certain behavioural and emotional responses towards getting special attention or preferential treatment from parents as they needed more care and effort during treatments and because of their CHD prognosis. As described earlier, children showed their happiness when visiting the hospital to get time alone with their parents. A strong parent-child bond was perceived by both children and parents. For children spending time playing with parents was the indication that made them feel loved. The following are the reasons children provided when asked (why do you love your parents?):

"Yes, they play with me" (Adil- child).

"We play hide and seek" (Ali- child)

"They are my family ... mom give birth to me... dad bring stuff for
me" (Kamal- child)

One of the children drew his family members around a small picture of his house. He also drew a little red shape of his heart (see picture 7.3).

Picture 7. 3: Child's drawing (Mohammed)

Parents, on the other hand, thought that they did not spend much time with their children because of time restrictions or job responsibilities.

> *"Because of the time.. when we are back home its almost in the evening" (Hilal- Hadi's father)*

> *"I only get to spend two or three hours with her" (Salim- Sara's father)*

A strong child-parent bond was reported by parents, who explained how much their children with CHD were attached to them. One mother clarified that she is very attached to her son and this led him to be attached to her and wanting to be around her all the time.

> *"Maybe because I am attached to him, so he becomes attached to me … We stay together all the time… If I am going somewhere, I have to sit with him and explains that I want to go to see my friends .. he would say (no I want to go with you)" (Maha- Maher's mother).*

Loss of a beloved family member

Two of the children had experienced circumstances where a family member had died, whom both of the children were close to. The two children had to deal with their emotions towards the death of these family's members, and they expressed that to their parents. For Kadi, who was a five year-old girl, her grandmother had died two months before her interview. As described by her mother, the grandmother lived with them in their house and Kadi spent time taking care of her grandmother. When the grandmother died, she missed her so much and asked about her many times.

> *"She [Kadi] took care of her grandmother… Her grandmother she died two months ago, and she misses her grandmother. Sometimes she says I want grandma and we would tell her she died.. and she says [Hana is quoting Kadi], (ok, fine bring her from God it's enough.. ok, bring any old woman to live with us at home). She always repeats that". (Hana- Kadi's mother)*

The other child, who had experienced death in his family, was Kamal a 10 years old boy; he noticed his sister suddenly had spasms when they were playing at a theme park. His mother reported that the incident happened in front of her son, who was seven years old at that time. He accompanied his father when they took her to the emergency room, and after four days, she died. After this incident, the mother described her son experiencing events when he was crying because he missed his late sister.

> *".. he had a sister.. younger than him.. she died.. she got spasms in front of him.. she was with him and his father at the theme park, and she got spasms in front of him, and they took her to the emergency room.. she spent 4 days in the hospital and then she went into a brain death.. so it caused him… what can I say? … it's like an accident to him... I mean she got spasms in front of him ..*

and he went to the hospital with his father to take her there… I remember when I told him that she is dead, he started to laugh.. he couldn't believe it… I would always find him crying … [silent for seconds] … and if you would ask him what it is? He would say (I remembered my sister)… when I had my youngest daughter .. he started to feel better". (Kamela- Kamal's mother)

Remarkably, these children in their interviews did not mention the death of their dear family members. When asked about their homes, and who lived with them, they did not mention the grandmother or sister who died.

7.3 Schooling

Some children behaved differently at school than at home, and some children used the fact they have CHD to skip school work. Going to school is one of the child's daily life activities, which could be affected by living with CHD and the associated time away to attend follow up appointments, surgical interventions, and hospital admissions. This section presents findings from children's and parents' reports about the children's feelings towards going to school, and their behaviour at school.

Feelings towards going to school

To help the children talk about their schools, the researcher asked them to draw their schools, to talk about what they liked about their schools, and how they felt towards the schools. All children who went to schools or kindergartens reported positive feelings about going to school. They loved going to school and the reasons were that they loved their teachers, and enjoyed the schoolyard.

Mohammed drew his school with a big yard, and described his school as:

> *"Everything in school is like home… there is a class room and schoolyard.. because it's pretty" (Mohammed- child).*

On the other hand, Leen and Sara talked freely about their schools without having the researcher asking them to use drawings or pictures. Leen did not say why she liked her school. She kept repeating:

> *"I love the school... but the school is beautiful" (Leen- child).*

Yet, Sara mentioned their teachers as the reason for her to love going to school:

> *"I love my teachers" (Sara- child)*

Other children, Ali and Kamal, who were 9 and 10 years old, reported logical answers to "why you love school?"; they loved the school to learn and study.

> *"It's a school.. I learn at it… I learn there because I want to become a doctor" (Kamal- child)*

> *"Just like that.. because I study and I can go to high school (Ali- child)*

In contrast, a child reported not liking the school and that failing at school is one of the things that made him angry or upset with going to school. He did not want his family to be upset if he fails. Also, it was noted during the interview that he had a tongue lisp or stutter.

> *" It makes me angry.. that.. I .. I failed at school and my family are upset with me because of that" (Fahad- child)*

Behaviours of children with CHD at school were only reported by their parents. Children only talked about how they liked their schools, their

teachers, and playing with friends. Upon the reports from the teachers, parents reported behaviours of their children at school. Parents compared their children's behaviour at home and at school and reported positive behaviour at school:

> *" He [Mohammed] is very quiet [at school]... I mean he is different at home" (Mariam- Mohammed's mother)*

Or, the comparison was made between the child with CHD and their sibling's behaviour at school. Farah described her son's behaviour at school in comparison to his twin brother's behaviour:

> *"They say [the school] that he [Fahad] is very polite and he is different from his twin" (Farah- Fahad's mother)*

Other parents reported complaints from school about their children's negative behaviour in terms of them crying too much. Indeed, one father described that his son's crying was "annoying":

> *"They [the school] complain about him .. they did complain…because he sounds annoying when he cries" (Hilal- Hadi's father)*

Another mother reported that her daughter's school complained of her daughter's frequent sleeping at school. Moreover, this mother perceived her daughter as being "normal" and she kept mentioning this at different points during the interview:

> *".. it's only about the sleeping sometimes.. sometimes she goes to school and wants to sleep .. but other than that, she is fine everything is normal with her" (Hana- Kadi's mother).*

Furthermore, Ali who was a nine year old boy, wished to be the best at school as he told his father. This wish of wanting to be the best also came through when playing with friends. His father described this desire of his son:

> *"He [Ali] wants to be the top in everything (I don't want anyone to be better than me) even when playing PlayStation, he wants to be the best ... Even at school .. he is the first .. his picture is on the school wall… (dad I am the best at school .. It's impossible to get me out of school because I am the best)" (Ahmed- Ali's father)*

Furthermore, Ali's father, Ahmed, described how he used to visit the school to check his son's progress. Interestingly, even though the school told him about his son's school achievements, he would tell his wife the opposite. He would tell his wife that their son was not good enough and he reported that by doing this, his son would study harder and his mother would push him further. This report from Ali's father suggests a high expectation of Ali to perform at school and an urge to push him further to be the best.

> *"I go to his school and the teachers says that your child is very, very good.. and they complement him.. and when I go back home I would say to his mom (they are very upset).. [laughing] .. and she would say (why? I find him very good)….. I would say ..they say that he can't write properly and he can't remember things.. so she would be pushing him harder" (Ahmed- Ali's father)*

Another example of how parents push their children to do better at school came from Sara's father; he reported that he would get angry with her if she fails at school. Remarkably, he made a connection of her memory issue to the CHD condition, as he said:

> *"Sometimes when she fails [at school] I get angry with her… I think her memory is a little bit weak... My doubt is that it is maybe because of her condition" (Salim- Sara' father)*

The above reports of parents showed the parents' roles in children's schooling and regarding the stress from school for the children with CHD. These reports suggest parents can induce further stress in their children with CHD as they push them hard to perform well at school or get angry with them when the children do not meet the expectations of their parents.

7.4   Friendships

The friendships for children with CHD were connected to the child's awareness of their CHD or how the child felt towards CHD. They had to make decisions about whether to tell friends about the news of their condition, and the reasons for their absence from schools when they needed to go to the hospital. In this section, children's self-perceptions will be presented about their friendships at schools and making friends with children who have similar heart conditions. Also, there were connections found between anger and fear issues in children and their relationships with friends, which led the children to get into fights with each other.

All children reported being happy to have friends at school or outside. Children were asked about their willingness to make friendships with other children who have CHD to identify if they felt more connected to them than healthy children, which was dependent on the child's awareness of CHD. For the child who had no awareness of their heart condition, the researcher asked if they wanted to be friends with any sick children at the hospital.

Some of the children showed interest in being friends with CHD children at the hospital where they can meet such children. However, these children did not try to make the friendship or approach other children with CHD but reported that they would feel happy to do it. To help them identify their feelings, the researcher let the children use emoji faces. They picked up happy faces; then the researcher asked them what this face meant to them.

" I feel like I am happy [to be friends with children with CHD]"
(Hadi- child).

Having a common trait could encourage children to be friends with children
with CHD. Kamal reported a reason that would make him want to be friends
with children with CHD; he thought that it would be a good idea providing
they would play with him, and if so they would share the feeling of tiredness.

"Maybe…. Because if we [him and children with CHD] get tired,
all of us will get tired together .. one tiredness [laughed]" (Kamal)

For Fahad, who was an 8 years old boy, although he was interested in making
friendships, he thought that the hospital was not the place to be friends and so
he played with others. This was even though there is a playroom in the waiting
area for children and visitors in the hospital.

"I like it.. but not in a place.. not here.. at the hospital.. but maybe
outside at the garden with people…Because this is a hospital and
people are sick how can we play?" (Fahad- child).

In fact, Fahad had an incident when he tried to approach a child in the hospital
to be friends, but the child refused to talk to him or play with him. This
incident made him feel shy, as he reported:

"But some of them... I tell them lets be friends they tell me (no)… I
felt like.. I mean.. that's it.. I was shy.. and I went back to my
place" (Fahad- child)

Another similar incident happened to Sara. Other children at the hospital
turned her down when she asked them to play, and they refused. However, she
was still interested in being friends with other children who had undergone the
same heart operations as she had:

> *Researcher: Would you feel happy if you became friend with kids*
> *who see the heart doctor?*
>
> *Sara: "Yes, happy... I said, do you want to play with me? They*
> *said no."*

On the other hand, Mohammed was unwilling to be friends with children who
had CHD for a different reason. Mohammed reported that he did not want to
look for friends with CHD because there was no other child who had the same
heart operation as him or who had visited his doctor:

> *Researcher: Do you want to look for kids who have an injection*
> *(he described his surgical scar as an injection) like yours and who*
> *goes to the same doctor?*
>
> *Mohammed: "No, he [the doctor] has no one like this".*

Maher and Adil, who were 4-year-olds, declined the idea of making friends
with CHD children. And did not wish to say the reason.

> *"No, it can't be" (Adil- child)*

Maher described an occasion where a child was laughing at him in the
playroom, which made him unwilling to try making friendships.

> *"No, I don't talk to them... Because this boy was laughing at me*
> *... There.. in the playroom.. because he was about to laugh"*
> *(Maher- child)*

Having these children talk about friendships at schools revealed different
kinds of interest and caring relationships. Getting special treatment from
friends because of the sickness was reported by Leen's father. The friends at
school were aware of her heart condition and treated her gently because of
that:

"They [her friends] know that she is sick, so they become soft with her" (Latif- Leen's father)

Other significant features in children's friendship were, anger, fights, or scared of getting hurt, which were related to children's behaviour with friends. Anger was significant with children who mentioned fighting with friends at schools, which can give an insight into how some friendships can be stressful for children with CHD. When the researcher asked the children about things that made them sad or upset, they reported that they hated being hurt or for someone to hurt them. In response, they got angry, cried and fought back with their friends.

"I am afraid of getting hurt (Mohammed- child)"

"I don't like someone to fight with me" (Fahad- child)

Children would fight if other children fought with them. Fahad reported being angry when someone hurt him. He reported many times in his interview how much he hated someone to fight with him. He pointed at an angry emoji and said,

"They come to me and fight with me... I hurt them back... I feel that I am angry. I become like this [pointing at angry emoji]... like my heart is beating so fast... he [his friend] comes and pushes me, and I get upset" (Fahad- child)

Adil also reported crying when the friends hurt him, and he, in turn, hurt them back.

"They [his friend] shout at me.. and hurt me... I hurt them" (Adil- child)

Parents also reported their children being angry and becoming involved in fights with friends. One mother described her son's anger in relation to

fighting and described his behaviour as fighting whenever someone made him angry

> *"When someone makes him angry he doesn't talk.. he fights"*
> *(Kamela- Kamal's mother).*

This mother also reported Kamal's excessive crying, and she related the crying to his sensitive nature and stuttering (speech issue). She reported her son's crying and fighting with his friends whenever they made fun of him.

> *"He is.. like I said .. he is sensitive .. for example, if the boys are just talking and discussing he would cry.. if they said things about him .. he will cry, and he hit them like light hitting" (Kamela-*
> *Kamal's mother)*

Crying, and feeling fearful were combined behaviours when communicating with friends. Mohammed's mother reported that he cried a lot even when playing with friends and that was the opposite of what he reported in the interview about him never having cried (the mother was present during her son's interview).

> *"I think my child fears a lot even if someone is playing with him;*
> *he will cry immediately... I was surprised that he told you he never*
> *cry at all. It's the opposite; he cries a lot... if he feels that he*
> *doesn't want to play anymore, he would cry and say to the other*
> *kid (you have hit me) or something like that" (Mariam-*
> *Mohammed's mother)*

Girls, as well, got angry and cried over things but did not usually fight with each other. Only Sara, who, as reported by her father, fought with other girls at school. In fact, she was encouraged by her father to fight with whoever hurt her:

"...I tell her if she hits you hit her back. Don't go to the teacher"
(Salim- Sara's father).

Her father wanted his daughter to defend herself instead of getting hurt and crying. He reported one time when a father of a girl from the school came to him and talked about his daughter (Sara) fighting with the other daughter:

"...So I told him (your daughter is fighting with mine.. do you want her to stand and do nothing?).. I sometimes tell her ..if you don't defend yourself, I will be the one who hits you" (Salim-Sara's father)

This father wanted his daughter to be strong and not to feel different because of her heart condition; thus, he treated her strictly:

"I scold her .. when she does something wrong... I would take out the idea of her sickness and won't let this thing to be like a barrier between her and her sisters". (Salim -Sara's father)

7.5   Child sharing news of their CHD with others

This section presents children's self-perception on their willingness to share news of their CHD with friends or others. This involves sharing information, such as their experiences of living with CHD, visiting hospital and undergoing surgical procedures. How they shared this information was primarily dependant on how much these children were aware of their condition. It was noted during the interviews that some children were lacking awareness of their CHD. So, in the interviews, only children with an awareness of their conditions were asked about their perceptions on sharing information with others. Further findings regarding children's awareness is presented in chapter 9.

Children talked freely about their willingness to tell others about their conditions without the need for the researcher to use the art-based approach with them. They were found to be selective in telling their friends or others about their conditions. For example, they selected certain people to share this information with, and hid it from others. For example, Fahad felt it was fine to tell only some of his friends at school about his CHD condition. However, he reported that his friends knew accidently when they overheard some teachers talking about Fahad's condition:

> *"Some of them know... They [friends at school] hear other*
> *teachers talking to each other's and they hear them talking [about*
> *the condition]" (Fahad- child).*

On the other hand, Ali reported that he let his friends know about his hospital visits but not the reason behind the visits. He wished not to tell his friends about his CHD. In addition, Kamal talked about his condition and hospital visits only to family members and never to his friends. Two of his friends, who were also relatives of his, also had CHD conditions and they were the only ones who knew about his condition. Having a common trait might explain him feeling comfortable sharing the CHD only to them. He gave his reason for not telling these friends:

> *"Why should I tell them [friends]? .. actually two of them [the*
> *relative friends] they have the same as I got" (Kamal- child)*

Hiding the information and never telling anyone about the condition, was the preferred behaviour for Mohammed. He did not wish for other children to know about his condition, as he reported:

> *"I am the only one who knows... I don't want them to know... Even*
> *my classmate, I don't tell them... Because the kids will tell their*
> *parents... I don't like telling anyone" (Mohammed- child)*

Mohammed said that if anyone knew about his condition, he would feel upset:

>*"Of course I will be upset" (Mohammed- child).*

Parents also reported some level of hesitancy in sharing the news of their children's conditions with their children or with others. Further discussion around parental influence on children, and the cultural impact on children's and parents' perceptions of sharing condition's news with others is presented in chapter 9 and 11. The following are some quotations that explain parents' reports about sharing news with others. Parents' self-perceptions were not directly related to their children's behaviour of sharing news with others; however, their reports can help to understand the family's background and sociocultural stresses which might impact on children's perceptions:

>*"Well.. it [the news of CHD] was between my husband and me.. even my family didn't know about it, only recently they knew.. I don't like to tell things like this.. you know" (Kamela- Kamal's mother).*

>*"No .. no, I am not planning to tell her [telling her daughter about her CHD] even her brothers don't know.. Just me and her father know about this… Honestly, I don't wish to tell... I don't want to talk about it… No, it's just.. everyone should leave it for the will of Allah [God] ... rumours will be bigger about her and that she has got this and that .. so, we left it to Allah" (Hana- Kadi's mother).*

7.6 Summary

This chapter presents findings from parents and children about children's behaviours and emotions in relation to the sociocultural stress of living with CHD. Children's relationship with their families was characterised by feelings of love and admiration as perceived by the children, despite the jealousy and fighting between siblings. Caring and empathy towards family members were common features in children with CHD, as reposted by parents. In addition, parents and children with CHD reported strong parent-child relationships and attachment. In terms of schooling, children's behaviour at schools was different from their behaviour at home, as reported by their parents. Children themselves reported enjoying school and participating in school activities. However, some parents had expectations for their children to perform highly at school and reported being strict when their children performed less well or were failing at school. This could also provide an insight into factors inducing stress for children with CHD.

Moreover, children's friendships provided an insight regarding their behaviour and emotions towards dealing with friends. Crying, fear, anger and fighting between children with CHD and their friends at school were commonly reported by the children and their parents. In relation to sharing news of CHD with others, children made choices as to whether to share the news of having CHD with others which can imply a sociocultural stress on them. Children were found to be either selective in sharing the information about CHD with certain people, or unwilling to share any information with anyone. Some parents as well were found to be unwilling to share the news of their children's condition, either with their children or with others.

Chapter 8

Sub-category: Physical changes stressors

8.1   Introduction

This chapter presents findings about the sub-category of physical changes the children had to deal with as part of having CHD. Children can face the stress of having physical symptoms e.g. easily getting tired when playing, and physical changes e.g. chest scar from heart surgery (see Figure 8.1). This chapter explores the children's behavioural and emotional reaction towards the stress of these physical changes. Both children's and parents' perceptions are presented regarding the children's behaviour and emotions.

Figure 8. 1: Concepts of sub-category: Physical changes stressors
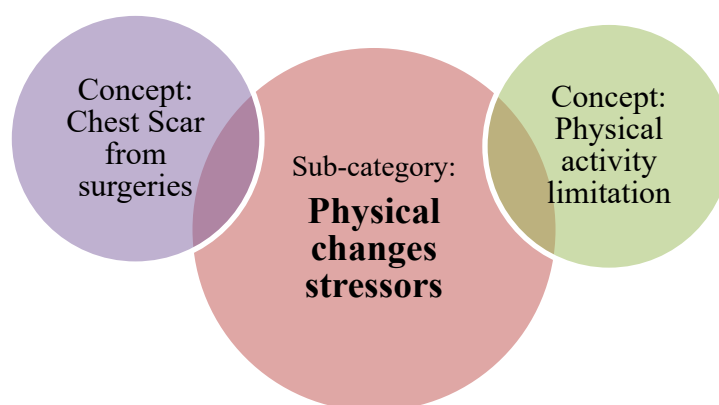
8.2   Physical activity limitation

Children with CHD exhibited physical symptoms like abnormal fast heartbeats and breathlessness during playing. They perceived themselves being "Upset" whenever they got tired while playing. Getting tired whilst playing can act as a stress for young children with CHD, who loved playing and being active. They also compared themselves with their healthy peers in terms of who gets tired easily. Children described the symptoms they had when playing, and how they felt towards these symptoms. On some occasions, the children were asked to use the emojis or drawings to help them describe their feelings. If the child talked freely about their feelings, no art-based approach was used.

Unusually fast heart beats and eventually getting tired was one thing Kamal did not like about himself. He liked bicycling as his heart did not beat as fast as it did when running in football games. He also reported needing to rest for a whole period in the school day because of being tired:

> *Researcher: what are the things that you don't like with yourself?*
>
> *Kamal: "If I run, my heart beats fast, I get tired ... Bicycle is light. It [his heart] doesn't beat as much as in the football.. just a little bit"*
>
> *Researcher: so your heart would beat fast and what would you do?*
>
> *Kamal: "I get rest until.. for the whole recess period in school"*

Ali also reported similar feelings of getting tired when playing football at school which made him feel sad. He enjoyed using the emojis to describe his feelings or how he looked during the play. He reported his parents' instructions to him when playing, which can bring an insight about how parents deal with children's limited physical ability.

Researcher: Do you get tired when playing?

Ali-child: "Yes, and I drink water... I sometimes get too much tired, and sometimes I get a little tired.. like this [pointing at face with tears].. my tears would be fallen like this…It [his heart] it would beat.. and if I set down I would become like this [pointing at a happy face]"

Researcher: what would you feel when get tired easily (showing emojis)?

Ali-child: "yes .. yes I would become like this [pointing at a sad face]"

Researcher: What would your parents say if you get tired?

Ali-child: "They say don't run .. run slowly"

However, following the instructions of his parents, Maher avoided running or jumping. He also reported getting tired when playing and described his tired feeling as having a fever.

Researcher: do you play like running and jumping?

Maher-child: " No .. no I fell down if I am running.. dad told me"

Researcher: Do you get tired?

Maher-child: "Yes I get tired.. like I have fever"

Parents, as well, reported their children being physically active, yet easily getting tired. Parents provided detailed descriptions of their children's symptoms when playing; for example, getting tired, becoming blue or green as their oxygen saturation levels reduce, or the heart beating more rapidly than normal. Most of the children were reported by their parents as enjoying being

active; however, they had to compensate for the tiredness and stop running or playing in order to get rest. Salim described the physical activities of his daughter, Sara. He also described what things he observed in his daughter, when she got tired whilst playing:

> *"She plays everything.. running.. football.. the bouncer… She plays, and plays, and plays and when she gets tired, she would get rest… The tiredness appears on her.. it is when she becomes blue.. her lips and fingers.. and her heart beats .. I mean if you are sitting next to her you can hear her heart beats, it will be very fast.. you can feel it.. and when you put your hand on her she would be like the vibrator.. these are the things that we can see".*
> *(Salim- Sara's father)*

Another mother described the symptoms of her son when he got tired whilst running. She reported her conversation with the doctor explaining to him how tired her son felt when he ran. Her son, Adil's, condition was stable after the first heart surgery and with follow up appointments and the symptoms of tiredness and low oxygen level, he was identified with the need for second heart surgery:

> *"I told him [the doctor] that when he [Adil] is running he gets tired .. he says that I am tired and he sits down.. so he [the doctor] made him to run in the hallway to see… can you imagine? When they measured the oxygen again it was 40% .. so the doctor said.. (of course there is a long [waiting] list but since he gets tired like this, we will do his operation as early as possible)" (Aida – Adil's mother)*

The symptom of a low oxygen level was also reported by Maha, Maher's mother. She described his lips turning green in colour as a sign of a low

oxygen level when jumping and playing football, although he enjoyed being active.

> *"I mean playing .. jumping.. walking up and down .. he gets tired ..*
> *he plays football, he likes football.. he likes to be active, but I have*
> *noticed something.. that when he is doing a big effort, his lips turn*
> *green .. I mean around his mouth. So, they [at the hospital] have*
> *told me its normal" (Maha- Maher's mother)*

Nevertheless, during her interview, Maha used to report how "normal" her son was during the physical activity, as well as on other occasions, despite describing his symptoms of tiredness:

> *"… I really find him better than others .. he is .. what to say ..*
> *more than normal.. even among his brothers" (Maha- Maher's*
> *mother).*

In contrast to parents who reported their children as physically active but easily getting tired, other parents described their children as being "lazy" because they do not move a lot. One mother was unsure if her son was lazy or tired of activities. She was then able to relate her son's low activity as being caused by his heart condition:

> *"He is basically lazy, or gets tired ... I guess it's because of his*
> *heart" (Kamela- Kamal's mother)*

Although his son did not complain of tiredness when playing, one father reported his perception of his son as being fat and lazy compared to his brothers. This was even though the child did not appear overweight and he was rather active during his interview. Hilal, Hadi's father, explained that his son stopped getting tired after the heart surgery was done:

The researcher: he does not get tired now?

Hilal: "no, nothing"

The researcher: even if he runs or climbs up the stairs?

Hilal: "Yes.. he is ok.. but I think he is a little bit fat.. unlike his brothers.. maybe umm.. he is a little bit lazier than his brothers"

Comparisons to others were also noted in children as they compared themselves to others. They compared their activity capacity for playing with their healthy peers. Children perceived themselves as getting tired more than their healthy friends, which added to their feelings of frustration as they could not compete with their friends:

Kamal- child: "I am more [more tired] than them. ... if I would play for a long time… I get tired more than them"

Researcher, what do you feel if it happens?

Kamal- child: "lots of things I will be missed.. I wouldn't find water at school .. it would be finished".

Parents also talked about their children getting tired when playing compared to their friends. Despite Ali's self-perception of getting tired more than his friend, his father reported the opposite about him.

"He [Ali] plays football and enjoyed that… He gets tired just like other kids". (Ahmed- Ali's father)

Another father compared her daughter's activity to her sister. After she had undergone her first surgical operation, the father reported that Sara was not as active when playing as her younger sister:

"She can play but not like her younger sister" (Salim-Sara's father)

Children with CHD compared themselves to their healthy peers, which could make them feel different, and less capable of playing or competing with their friends. From the above findings, it is noted that children can face the stress of being less active compared to healthy peers.

8.3 Chest scar from heart surgery

The presence of chest scarring is discussed in this section as a concept in the physical changes of a child who had experienced heart surgery, and how the presence of the scar made the child with CHD feel and behave. These changes can impose stress from dealing with the scar as an interrupted physical self-image, and affect the way they felt and behaved towards their physical changes.

To help children talk about their scars, the researcher let them draw themselves and their hearts. They were then asked: *how do you see yourself? Is everything okay with you?* If the child talked about the operation, the researcher asked about the scar. The children were then able to describe their physical appearance such as they looked pretty or nice. Some of them talked about the scar on the chest and how they felt about its presence, while others only described the size and location of the scar. Feelings were also ascertained by the use of emojis faces. Seven children had surgical operations and only five of them mentioned their scars. The other children mentioned their surgery but did not talk about the scar on their chest.

Some children described their scars on their chests, the location of the scar on their bodies, but did not report how they felt about it. For example, Leen explained her operation site and the scar on her body pointing at her chest:

"They did an operation to me, yesterday [in the past].. They did here [pointing at her chest].. and injection [scar] here .. and this.. this, and this" (Leen- child).

Hadi also talked about his scar and described where it was located on his body. He perceived himself as happy when I asked if the scar made him feel upset.

"So, from here until here [showing the scar on his chest] and from my back and from here… No, not upset. I was happy when they did that [the surgery]" (Hadi- child)

Some parents and children chose to either talk or not to talk about the presence of the scar. Those parents covered the scar and asked their children to cover it as well, to protect their children's feelings, and stop them from thinking about it and becoming sensitive. One mother explained that she was trying not to talk about the CHD with her son, and hiding the chest scar from others, because of her concerns about her son. She did not want him to live with the idea of being a "sick child":

"We [she and her husband] are trying not to talk about it [CHD]. I cover the scar.. I don't want the other kids to see it. I don't want him [Mohammed] to concentrate on it… They would know his weakness point. I don't want him to get sensitive about it or be aware of it .. I don't want him to get inside the (picture of a sick child)" (Mariam- Mohammed's mother)

Indeed, her child, Mohammed, reported that he did not see his scar even though he knew that the scar existed. He reported his awareness for the presence of the scar by saying:

"There is an injection [scar] here [pointing at his chest]". (Mohammed- child)

However, Mohammed refused to talk about the scar by denying he had seen it:

> *Researcher: When you see this scar, what do you feel?*
>
> *Mohammed: "I don't see it."*

The fact that Mohammed refused to see his scar can be linked to his mother's desire of not wanting him to see it and how the mother can influence her child's behaviour.

In addition, the chest scar caused doubts for Ali who had had heart surgery. Ahmed, Ali's father, reported how his son was feeling because of his chest scar and that he compared himself to his brother:

> *"... once, he [Ali] was talking to me (Why I am like that dad?) ..*
> *(Why did they do this on my chest?) .. (My brother has nothing*
> *like this)... I told him when you were younger something happened*
> *and the doctor said that he had to check your heart .. but you are*
> *just like your brother". (Ahmed- Ali's father)*

Adding to Ali's feelings towards the scar, the father reaffirmed that his son did not feel bad or sad about the scar on his chest, and that he asked about it only out of curiosity:

> *"No, he is not feeling bad... it was just a question .. like something*
> *in his chest [the scar] .. I mean he was curious .. nothing more".*
> *(Ahmed- Ali's father)*

8.4 Summary

Children with CHD experienced physical changes due to having CHD, such as low activity level, and a chest scar from heart surgery. These changes are proposed as sources of stress when they tried to meet their activity levels to their needs for playing and running. Some children perceived themselves as getting tired more than their healthy peers when playing, which caused them to feel sad and upset. Moreover, some children doubted the presence of a chest scar after the heart surgery and asked their parents about it. Some children described the location of the scar on their bodies without reporting feeling bad or disliking the scar. The next chapter presents four factors which are suggested to influence the children when facing the three types of stressors discussed earlier.

Chapter 9

Influencing factors

9.1   Introduction

This chapter presents findings from children and parents which provided a perspective to four factors influencing the children when facing stressors. These factors are children's awareness of CHD, parental influence, children's speech and recall issues/ delays, and family's immigration. Looking at the perceptions of parents and children, it was interpreted that these factors were affecting the way the children dealt with stressors related to having CHD. The following presents children's and parents perceptions under the subheading of each influencing factor.

9.2   Children's awareness of their heart condition

This section describes children's awareness of their heart conditions and their reactions towards the news of having CHD. Parental proxy reports about the children's awareness are also demonstrated in this section, thereby supporting the children's perceptions. Eight of the children became aware of their CHD conditions either through their parents discussing the condition with them or they identified it themselves because of frequent hospital visits. Unexpectedly, the concept of children's awareness was generated from the data as it was noticed that two of the children were unaware of their conditions or the reason behind their hospital visits. Those children were not aware that they had gone through surgical operations, and they did not know the reason for their hospital visits for many reasons demonstrated in this section. Moreover, all children, through their feelings and behaviour, reacted to their awareness or unawareness of their hearts conditions. Thus, it is important to understand children's emotions and behaviour through their awareness of the condition.

To encourage the children to talk about their heart conditions, the researcher asked the children to draw pictures of their hearts, and were asked what did the heart look like and to elaborate more as they drew. The researcher also showed the children pictures of many hearts in different sizes and colours and asked them to choose one heart that looked like theirs and talk about it. The topic of children's awareness of their condition then began to emerge.

Some children, who demonstrated awareness of their condition, described their happy feelings about having CHD, while, other children reported negative feelings:

> *"Angry ... sad.. and I want to scream" (Adil, child)*

Ali related his sadness to when his heart beats rapidly:

> *"No I am not sad .. because .. when my heart beat rapidly, I become sad" (Ali, child)*

Other children were unaware that they had a heart condition; unawareness was demonstrated at different levels in two children. During his interview, Maher, who was four and a half years old, demonstrated a lack of awareness of the location of the heart in his body as well as his CHD condition. He pointed at different body parts (his wrist) when asked about the location of his heart. Likewise, Mohammed, who had a scar from the cardiac surgery of their VSD repair, did not know why there was a scar on his chest. As described earlier in Chapter 8, Mohammed knew that the scar existed but denied that he could see it.

For other children, even though they were aware of their conditions, they were missing the awareness of some details of their journey with CHD management. These young children did not know why they were getting check-ups and visiting the doctor at the hospital, and that they only go to the hospital whenever their parents told them to.

"Because dad told me to" (Maher, child)

"Dad took me to here" (Hadi, child)

It was noticed that some children, even though they were aware of their CHD conditions, denied it at some other points in the interview.

"I have nothing" (Fahad, child)

"It's not tired [his heart]…Nothing in my heart" (Hadi, child)

Indeed, Fahad did talk about his condition and described what he had with his heart as "heart stress" and this was the reason he provided for the hospital visits. He also revealed having a device which was placed inside his heart. He drew his heart as a perfect red heart next to his home drawing (see picture 9.1).

"because I have got heart stress [unclearly pronounced]… a device" (Fahad, child)

Picture 9. 1: Child's drawing (Fahad)

Moreover, children who were unaware of their CHD, seemed inconsistent or unsure about their feelings towards the CHD or towards going to the hospital.

Maher, for example, mentioned that he liked going to the hospital, but later in the interview when asked about his feeling, he said,

"I don't like it". (Maher- child)

Parents, as the primary guardians of their children, played an essential role in their children's awareness of their conditions. Parents decided to keep the child aware or unaware of their conditions according to their own beliefs and experiences. Thus, parents' beliefs were found to influence their decision to discuss CHD with their children. Parents protectiveness of their child, as described earlier in Chapter 8, could be influenced by the idea of how vulnerable their children were, and an awareness by the parents that their child might easily get hurt by others. Parents not only decided to hide information about the CHD from their children, they also hid this information from schools or other family members such as grandparents. Mariam was concerned that other children might take advantage of her child's sickness and hurt him. This mother was also afraid to inform the teachers at school about her child's condition. She developed these thoughts as she had heard a story of two sick children who lost their consciousness when a teacher was scolding them at school. She believed that if the teachers knew about her child condition, they would intentionally hurt him.

"They would know his weakness point ... I am afraid of him being hurt, and I am afraid that he would tell his friends". (Mariam, Mohammed's mother)

Hana reported the she and her husband believed that by hiding this information, they could protect the grandmother from being overly concerned or worried about her grandson.

"We were concerned that she might be worried or afraid so we didn't tell her" (Hana, Kadi's mother).

Other reasons for not telling the affected children about the condition, according to parents, was to prevent their children from feeling isolated, from avoiding playing with other children, and from overthinking about their condition. Ali's father explained that he did not want his son to know about the condition because he believed that thinking about the condition would prevent him from interacting with other children.

> *"He would be cautious like he won't play with the kids .. and he would think that he is sick so he would get away from them.. and he would become isolated ... His thinking would be all the time around this condition". (Ahmed, Ali's father)*

Ahmed also believed that if his son lives like a sick child, he may use the sickness to create problems:

> *"I mean every problem he might have relate it to the heart condition .. for example, he would make problems.. or .. umm .. he won't take care of himself". (Ahmed, Ali's father)*

Furthermore, with the intention of protecting their children from emotional or psychological harms, some parents wished for their children to remain unaware of the condition, believing that awareness would make their children feel scared or different. Even though some parents told their children about their conditions, they reported that they later regretted discussing it with them and wished that their children had never discovered about their conditions. The following are statements from parents whose children were aware of the condition:

> *" I was hoping that he won't know about his heart.. but he understood everything by himself ... I don't want something to affect him emotionally". (Aida, Adil's mother)*

> *"I didn't wish to tell her.. I didn't want to talk about it ... She*
> *might get scared ... If someone would tell someone that you have*
> *got this and that, the person will be broken.. even if it's a child..*
> *they can feel it". (Hana, Kadi's mother)*

Even though Ahmed did wish for his child to remain unaware, he explained the condition to his son, Ali, who started to feel different when he noticed the special treatment he was getting from his grandmother:

> *"[Ahmed reporting his son asking] (Dad how it's like this?... I am*
> *fine.. I have nothing... why does she [the grandmother] say I had*
> *an operation and all?)" (Ahmed, Ali's father).*

In response, Ahmed explained the condition and the operation to his son. In fact, he believed that his son was not overthinking or worried about the condition, and that made him feel that he had succeeded in protecting his son.

> *"Yes, I feel it is one of the reasons why I didn't wish for him to be*
> *aware.. someone to take advantage of him ... I would say he is out*
> *of the idea of him being sick". (Ahmed, Ali's father)*

Some of these parents gave their children misleading information or changed the subject whenever their child tried to talk about the condition, in an effort to hide the condition from them. For example, the following is a quotation from Hana who made her daughter believe that she was visiting the doctor because she had flu. She explained that her daughter already had flu, and when she asked her mother about the reason for her hospital visit, the mother did not wish to let her know about the actual reason.

> *"I told her yes because of the flu ... Even if she asks [about the*
> *heart ultrasound] I would tell her it's because of the flu and*
> *because you are coughing, so they are checking your chest".*
> *(Hana, Kadi's mother)*

Similarly, Ahmed reported changing the subject whenever his son tried to talk about the CHD:

> "He knows that he has an issue in the heart. But.. if he starts the
> conversation about it with us, we .. we change the subject".
> (Ahmed, Ali's father)

Doctors' advice had a link to the parents' decision not to talk to their children. Some parents reported being advised by doctors about not talking about CHD with their children. Moreover, it was noted that most of the doctors in this study did not talk directly to the children when explaining the condition's prognoses; they discussed it with the parents and made decisions with the parents only. Parents who wanted to keep their children unaware of the condition found it satisfying for doctors not to be discussing the condition with the children. Ahmed reported that the cardiologist was advising him not to discuss the CHD with his son, and explained to him that he should not talk too much about the condition to avoid making him feel like a sick child.

> "[Ahmed quoting the doctor] (you have to reassure him [Ahmed's
> son] and don't talk to him in a way that makes him feel he is sick.
> Just treat him like a human being. I mean normal).. He [the
> doctor] said if he talked to you about it just answer him with two
> words. And .. I mean .. answer him but change the subject".
> (Ahmed, Ali's father)

On the other hand, another parent had a contrary experience with another doctor. The doctor discussed the condition's prognosis and the need for heart surgery with the child. According to his mother, Kamal was in shock, even though she previously discussed the condition with him when he asked about it. However, he promptly started to be excited and told friends and family about the plan for surgery.

"The doctor talked to him and told him that you will have an operation .. you can say that he was in shock .. since then he was telling everybody about the operation... he was excited.. he was noticing the operation as a nice thing. He felt like it's an adventure to have an operation". (Kamela, Kamal's mother)

Moreover, parents were choosing to discuss or hide the CHD condition from their children based on their own beliefs of what their children could or could not understand although parents' attitudes towards this varied considerably. For example, some parents reported that their children were too young to understand, even if they would try to explain it to them, whereas others reported that all young children could not process these thoughts in their brains. Others believed that as long as the condition is not visible and cannot be seen externally, the child will not know about it and will experience no psychological changes:

"Children younger than six years old, they have no thinking process … I mean what does the child know? if you tell him you have a heart condition, she would say what is a heart condition?... As long as its [the condition] invisible or not external ... Like a disability… it won't affect her psychologically" (Salim, Sara's father)

"He is young. I mean he won't understand.. he knows that he takes a medicine…even if I talk to him he won't be able to understand… what does he understand about the heart?... I have not thought about telling him. But I have a feeling that he won't understand. I think if he is a bit older, he would understand himself" (Maha, Maher's mother)

"He has no idea about what he has got ... when he gets older [will understand], but now at this age! I think no ... they don't understand .. I believe" (Farah, Fahad's mother)

Inability to understand and having issues with recalling was reported by Leen's father, so that even after explaining to his daughter, she was still unable to understand or remember:

"We told her that you had an operation last time and this time you will have another operation ..she is not aware of what is happening to her... she knows that she has something in the heart ... she forgets" (Latif, Leen's father)

In contrast, one mother believed that sharing information of CHD with her son would be dependent on the severity of the condition. This mother thought that mild conditions should not be shared with the children, unlike severe conditions. She reported that it would be unrealistic if her child were to stay unaware of a severe condition, especially if there was a surgery in the plan:

"You see if the condition is mild, the child shouldn't know about it but if there is a possibility for an operation to be done, it would be difficult to shock him ... I would like to make him stop thinking about it. But at the same time realistically he has to know about it. I mean ten years old, he is old enough" (Kamela, Kamal's mother)

One factor that might have influenced parents' decisions about whether or not to talk to their children about their CHD was related to the parents' understanding and level of unawareness about the CHD symptoms, prognosis, or future treatment plans. Kamela, believed that heart pain could not be felt as she reported:

"[Kamela quoting her son] (he [a friend] hit me and my heart is hurting).. I told him. No your heart doesn't get hurt. You don't get

pain in your heart… I mean this extra part [describing the CHD
type her son had] in the heart is not painful. So, I don't want him
to be in delusions.. so I would tell him no your heart is not hurting
... I mean your chest might be tired because of running, but you
have got nothing with your heart" (Kamela, Kamal's mother)

These parents either could not find useful resources to read about the condition, did not think about reading and educating themselves, or did not feel like they needed to know more. According to some parents, emotional exhaustion caused by being a parent of a child diagnosed with CHD was a reason not to read about the child's condition:

" His [Maher's] father didn't wish for me to read.. because of my
emotions.. because I was really exhausted.. psychologically".
(Maha, Maher's mother)

Other parents, simply, did not know if they should or should not discuss the heart condition with their children. As Hilal said, he never thought about talking to his son about the condition:

"It didn't come to the mind [to tell him]" (Hilal, Hadi's father)

9.3 Parenting a child with CHD

Parents and their parenting styles for their children with CHD was also suggested as a factor influencing children when facing stressors; for example, some of the children got special treatments from their parents because of their conditions, whereas other children received firm parenting styles. Even though it was not reported directly by the parents or children, it was articulated in the parents interviews that the way they disciplined or treated their children with CHD was connected to how their children behaved and developed certain emotions. Only parents' proxy reports are presented in this section' children's

perceptions of their parents and siblings relationships were presented earlier in Chapter 7.

Preferable treatment was identified from some parents' descriptions of treating their children in preference to the other siblings. This can be related to the jealousy between the siblings as presented in Chapter 7. This was also revealed when parents reported that their child with CHD asked for attention, and the parents would respond favourably to them. An example was provided by Maha who justified the special treatment for her son with CHD as she felt sorry for him because the other children were "normal". In the quotation below, she also provided an example when she gave him the last piece of chocolate, which belonged to his older sister:

> *"Because you know thank god.. all of them are normal.. so I feel.. I mercy him ... for example in the fridge there was only one chocolate. So, I would say.. I know it's yours [Maher's sister] but you are older and you can understand so give it to him and I will ask your father to bring you some". (Maha, Maher's mother)*

This mother also reported incidents of jealousy between Maher and his siblings and she related this jealousy to the way she preferably treated Maher:

> *"everything will be for him first then the others. So, she [his sister] gets jealous because of this point"(Maha, Maher's mother).*

However, Maha was reassured that her son's behaviour of taking things from his brothers, was only noticed inside the home with his brothers, and not with other people:

> *"I am telling you if he does this stuff outside home, no I won't allow him. Thank god he is only like this at home ... because he doesn't do that outside home.. to make me say that he is selfish or something or that he will grow up like this ... And sometimes he*

pities his sister and tells her (I don't want it)". (Maha, Maher's mother)

Grandparents were also treating their grandchildren with CHD preferably, as reported by two parents. These parents reported grandparents spoiling the grandchildren because of their CHD condition. However, parents reported their frustrations over the way the grandparents treated their children and described their disapproval of this special care:

> *"His [Fahad's] grandfather, mostly, who spoils him… he is the grandfather's favourite... he says [Farah is quoting the grandfather], (he has got enough.. don't hurt him). I feel that it is not good. It's wrong but what can I do I have got nothing with my hand to change this". (Farah, Fahad's mother)*

This view was echoed by Ahmed, Ali's father, who described the grandmother as "overly protective" of Ali especially when playing with other children:

> *"My mom [Ali's grandmother] she feels overly protective of him… whenever mom saw him playing with the kids, she says [Ahmed quoting the grandmother], (be careful.. don't be harsh on him).. like that…I tell her mom don't do this.. she says [Ahmed quoting the grandmother], (No, I love him.. it's not your business)". (Ahmed, Ali' father)*

Furthermore, parents made comparisons between their children and showed preferences either to the child with CHD or other siblings. This behaviour by parents can explain children's feelings of jealousy and the rationale for fighting with each other, as presented earlier. For instance, Hilal, Hadi's father, on different occasions during the interview, compared his son who had CHD with his brothers. Hilal also compared Hadi's limited physical ability with his brother, see Chapter 8. Here is a quotation from Hilal demonstrating the comparison:

"Honestly, I don't see anything with him that is better than his
brothers, his brothers are better than him ... His [Hadi's] older
brother, especially, I think he is very smart". (Hilal, Hadi's father)

On the other hand, other parents made comparisons in favour of their children
with CHD versus the other sibling. Farah, Fahad's mother, talked about
Fahad's behaviour in relation to his twin brother:

"They are the opposite of each other as if they were not twins ...
and he [Fahad] is quieter than his twin". (Farah, Fahad's
mother)

On other occasions, children themselves asked for preferential treatments or
more attention from their parents. Children who were aware of their CHD
conditions, used to say words like "I am tired", or "I have had a surgery" to
get what they wanted and gain their parents attention. Aida, for example,
reported the link between her son's awareness and him being spoiled or acting
tired:

" I feel he became [After becoming aware of CHD] more spoiled..
he says [Aida is quoting her son] (I am tired.. I have flu ..I swear I
am tired) and starts to act like he is panting [out of breath]".
(Aida, Adil's mother)

Saying "I am tired" to avoid doing things was also reported by parents whose
children wanted to get out of studying and doing homework:

"...He says [Farah is quoting Fahad], (It's enough I am tired .. I
don't want to continue studying.. it's enough, I am tired)". (Farah,
Fahad's mother)

> *"...She does some studying then walks away for a while and comes back and says [Hana is quoting Kadi], (It's enough I am tired let me get rest)". (Hana, Kadi's mother)*

Salim reported similar behaviour of his daughter, which was revealed only at school:

> *"...She may use the fact she is sick at school with the teachers... For example, she doesn't want to go to school, or she goes to the school and she feels sleepy. So, she would say to the teacher [Salim is quoting Sara], (I am sick , and I can't .. I am tired)... So, sometimes she uses this excuse only at school". (Salim, Sara's father)*

Moreover, some children asked directly for attention from their parents, for example, mentioning their sickness whenever they wanted to get something:

> *"She says [Latif is quoting Leen], (Mom I am sick.. I have had an operation) .. and if something is missing at home like milk or something she says [Latif is quoting Leen], (Dad where is the milk? The doctor said I should drink milk)" (Latif)*

In a similar case, Farah described that when the family were having a birthday party for his brother, Fahad thought he deserved this party because of his CHD condition:

> *"He [Fahad] says [Farah is quoting Fahad] (because I had an operation). He would ask me to give him more of something ...[Farah is quoting Fahad], it's [a birthday party] supposed to be done for me because I have had an operation". (Farah, Fahad's mother)*

Other children indirectly asked for attention, as reported by their parents. Their parents reported them crying or screaming if they did not get what they wanted:

> " If you are on the phone and not giving him attention.. it [the screaming and crying] will get worse … If you don't give him [Hadi] what he wants he will cry". (Hilal, Hadi's father)

> "She [Leen] gets angry when she asks for something, and you don't bring it to her.. like a candy or chocolate… She cries and screams and like that.. she hit with her hand and legs and says [Latif is quoting Leen], (bring it to me).. and I give it to her, and that's it". (Latif- Leen's father)

It is important to report how some parents responded to their children's behaviour when the children wanted to get things, as this can provide an understanding of the children's fighting behaviour and feelings of anger. For example, Maha stated that she would respond to her son being angry by giving him whatever he wanted:

> Maha- Maher's mother: "He sometimes gets angry.. but I told you… I don't let him reach the point where he would be very much angry"

> Researcher: and what makes him angry?

> Maha- Maher's mother: "Ummm .. maybe.. for example.. when I don't give him what he wants"

Another example was mentioned by Hana about her daughter's, Kadi, jealousy and wishes for her mother not to talk to her brother. As she responded to her daughter, she stopped talking to her son and said:

"I don't like to make her upset. It's fine. I don't want her to be upset" *(Hana, Kadi's mother)*.

In other situations, parents reported that they felt their children were jealous or wanted more attention and to be the priority in situations such as playing and spending time with other siblings. These parents described situations where their children asked for attention in relation to feeling jealous of their siblings,

"If I am talking to her brother or holding her sister she says [Latif is quoting Leen], (All of you don't love me), and she hits her mother and tells her [Latif is quoting Leen], (You don't love me)". *(Latif, Leen's father)*

"I feel he wants attention … Especially if I am playing with his sister he would call me [Aida is quoting Adil], (I want to talk to you)" *(Aida, Adil's mother)*

"Yesterday I was with his sister and he [Maher] came in and started to make a mess and say [Maha is quoting Maher], (Oh mom come and see this) .. as if he wants to say .. more care for me … He wants me to give him the priority". *(Maha, Maher's mother)*

When it comes to disciplining their children with CHD, parents, particularly mothers, usually felt guilty about scolding them. Feeling guilty was a common theme in the initial parents' interviews, so in later interviews the researcher asked parents if they felt guilty when disciplining their children:

"Yes, of course a lot. Discipline is very hard, God help us". *(Kamela, Kamal's mother)*

"I pity him… Yes because of his condition. Even though he is very normal". *(Maha, Mohammed's mother)*

> *"I spank him and then I pity him, and I would feel that I did a*
> *mistake by spanking him". (Farah, Fahad's mother)*

Not all parents felt guilt toward their children's discipline. Fathers reported being strict about discipline to make the child strong and not to feel the sickness. Wanting a normal life for their children was a reason to be strict as reported by Salim:

> *"I spank her .. I would remove the idea of her sickness and won't*
> *let this thing to be a like a barrier between her and her sisters… I*
> *want her to grow up normally.. I don't want her to feel the*
> *sickness". (Salim, Sara's father)*

> *"..if I don't use the punishment he would make more mistakes".*
> *(Ahmed, Ali's father)*

9.4 Children's speech and recall issues or difficulties

Children faced the stress of having speech or recall issues in schooling and communicating with their families and others. These issues were noted during the children's interviews as well as from some parents' reports. Some children had been delayed in starting school or were behind their peers in studying because of their speech and learning issues. During the interviews the researcher noted the commonality of these issues among most of the children with CHD in this study; for example, stuttering, pronunciation issues, repeating words whilst trying to explain themselves, saying unclear words, or being unable to make clear complete sentences compared to their developmental milestones. These issues had even made it difficult to understand the children on some occasions during the interviews; therefore, the researcher tried to use more drawings and emojis pictures to help the children better explain themselves.

Parents reported their children's delays in school admission, as described by Latif about his daughter, Leen. He also made a connection between her speech issue and her CHD and explained that her speaking got better after she had her surgery:

> *"Her [Leen's] speech was totally different.. you can't understand what she is saying, but after the surgery, she started to be fluent… once she got out of the hospital, she started to talk, and even her voice changed". (Latif, Leen's father)*

Leen's speech issue was also noted by the doctor, who referred her to a special school that specialised in speech difficulties with children:

> *"..even the doctor, he asked her several questions but couldn't understand her. So, they said that she needs to go to a school here". (Latif, Leen's father)*

A speech issue affecting school performance was reported by Salim, as his daughter's, Sara, speech issue and reading difficulty impacted her learning at school:

> *"She [Sara] should be in grade three but we made her re-do grade two. The alphabets, she can read them correctly but can't read a complete word" (Salim, Sara's father).*

Salim described his concern and reported his daughter's need for follow up about her speech issues. Also, he described advice from the doctor regarding this issue:

> *"She [Sara] needs follow ups. There has to be a doctor who follows up with her. They [the doctors] said we have to finish with her heart condition first then we will see about the other issues". (Salim, Sara's father)*

Furthermore, recall issues or difficulties were reported for other children with CHD by their parents, which impacted their school performance:

> "She [Kadi] has a difficulty in recalling things. I feel that she can't memorise things fast.. and she forgets things easily.. she forgets things easily". (Hana, Kadi's mother)

> "They [the school] only say that he [Mohammed] is behind in memorizing. That's true, I have noticed that. I also have noticed that if he memorizes a new thing, he will forget the old thing". (Maha, Mohammed's mother)

Poor recall was also reported by Salim, who wondered if this issue, speech and recall, could be related to Sara's CHD condition:

> "I think her memory is a little bit weak... my doubts is that it is maybe because of her condition!" (Salim, Sara's father)

Another speech issue demonstrated in children was that of stuttering or tongue lisp. Kamal's mother described him as being "very sensitive" about this issue which made some of his friends at school tease him about it, as reported by the mother.

> "... you know he stutters when he talks, and his pronunciations.. for example the letter (J) he pronounce it (d)… I mean he is very talented and he like to read. So, he likes to talk about things he learned and when he talks fast and excitingly, his words come out wrong and the pronunciations is wrong.. they [his friends] would laugh at him. So, he is very sensitive from this side. So this is what made him to be shy". (Kamela, Kamal's mother).

9.5   Family immigration

Two families immigrated from their home countries to pursue treatments for their children with CHD in SA, either because of the war circumstances or to seek medical care for their children. Accordingly, in the process of immigration, delays in diagnosis, or in receiving treatments for the children occurred. Moreover, the children of immigrant families were noted to have speech and recall issues, which can be related to the late treatment and surgical corrections because of their immigration circumstances. The speech and recall issues of these two children were presented earlier in section 9.4. Only parents' reports are presented in this section.

Lack of medical resources and war situations caused delays in the diagnosis of CHD and receiving proper treatment, reported by parents of Sara and Leen, who described the time when their daughters were diagnosed with CHD and the treatment was delayed because of the limited medical care during the war. Consequently, there was a gap of three years between the time of diagnosis and receiving treatment for Sara, and a gap of one and a half years for Leen.

Latif described being powerless as all facilities, including medical, were shut down which caused them to have to wait for two years until they managed to emigrate to SA and for Leen to start receiving medical treatments.

> *".. but then the war was started, and that's it. We couldn't do*
> *anything. Everything was closed and embassies and everything*
> *was closed over there.. it's a war.. and she stayed like this for a*
> *while… she became two years old when we got here [in SA] she*
> *was two years old". (Latif, Leen's father)*

The other experience was reported by Sara's father, who explained how the treatment of his daughter was interrupted because of the war and delayed for several years:

"...We started following up in [a hospital in their home country]
first they were rescheduling [appointments]. A year and another
year and the incidents [the war] were ongoing. He [the doctor]
postponing it [treatment] to a year and to another year". (Salim,
Sara's father)

9.6 Summary

This chapter presented four factors that are suggested as influencing how the children faced the stressors. Children's awareness of CHD is one significant influence, which was demonstrated in children's reaction toward the stressors according to their level of awareness of their conditions. Parents had an important role regarding children's awareness if they did not wish to tell their children about the CHD diagnosis. Parents and parenting children with CHD was also an influence on children's behavioural and emotional changes, as children acted upon the way their parents treated them. Some parents treated their children with CHD preferentially because they pitied them for being sick. On the other hand, some parents treated their children strictly to prevent them from feeling different or not "normal". Children also, asked for attention from their parents and mentioned their sickness to their parents to get things or avoid doing things.

Additionally, speech and recall issues or difficulties in children with CHD impacted on their school performance and communication skills. Furthermore, dealing with speech and recall difficulties, and being children of immigrant families were interrelated and considered to influence children with CHD. For the families who immigrated to SA to seek medical treatments for their children, the immigration process caused delays in the children's diagnosis with CHD and treatments. The delay in treatments was noted with the potential of speech and recall difficulties developing in the immigrant children, thus affecting their learning and schooling.

Chapter 10 Theory Development

10.1 Introduction

This chapter describes the theoretical proposition of the relationships between children with CHD and their exhibited behavioural and emotional reactions. An overview description of the generated substantive theory is presented. Moreover, descriptions of the relationships and links of categories and concepts in the theory are also provided in this chapter.

10.2 Overview of the substantive theory:

A substantive theory that is developed to describe a phenomenon in a specified area and/or population (Glaser and Strauss, 1967). According to Charmaz, a theory develops by the researcher theorizing the participants' views of something concerning them and acknowledging that the researcher's interpretations of these views are essential in developing the theory (Charmaz, 2014). Thus, this theory emerged from the researcher's interpretations of deep analysis, notes from the interviews, and theoretical conceptualizing of data gathered from children with CHD and their parents. Memo writing, diagramming, and mind mapping assisted the researcher's theoretical thinking and the exploration of relationships between categories and concepts. At the stage of developing this substantive theory, the researcher developed a spider map presenting links between sub-categories and related concepts (Figure 10.1). By breaking down each sub-category into sections in the spider map, the researcher was able to examine the relationships between the sub-categories and reach the theoretical proposal of how children with CHD reacted behaviourally and emotionally when living with CHD.

The researcher proposes that as children live with CHD, they face different stressors. Their *reactions* to these stressors is the main concern for the children and the core category in this theory. The stressors are identified as mediators, which describe the process through which the stressor variables and

behavioural and emotional reactions are related. Moreover, in-depth analysis identified four factors that influenced the strength or type of children's emotional and behavioural reactions toward these stressors. It is suggested, therefore, that the four influencing factors are moderators. The substantive theory, therefore, was identified as the *children's behavioural and emotional reactions towards stressors related to living with CHD with the presence of influencing factors.* Figure 10.2 demonstrates the flow of this proposed substantive theory. An example vignette is also provided in a box alongside Figure 10.2, describing how a child reacts to a stressor and how this reaction was influenced by specific moderators. The purpose of using mediators and moderators in this current study is to help the researcher to find deeper connections and facilitate understanding of the complex relationships between variables (Children with CHD, and children's behavioural and emotional reactions) (Bhandari, 2021). Although mediators and moderators are commonly used in quantitative studies to statistically measure the relationships between variables (Cristescu and Băban, 2022; Ho, 2021; Mahipalan and Sheena, 2019), previous qualitative studies were also found using mediators and moderators to understand deeper relationships between concepts (Bate et al., 2012; Gómez et al., 2020). In a study by Bate et al. (2012), the qualitative analysis of interviews, which were conducted in India, identified mediators that explain causal mediating relations between the adolescent's involvement in a tobacco prevention program and their initiatives to use tobacco with potential moderators to tobacco use. Another example of using mediators and moderators in qualitative studies is demonstrated by Gómez et al. (2020), which included mediators and moderators in developing a conceptual framework and they found them helpful in theory development and identifying deeper relationships between concepts. Through identifying mediators and moderators, Gómez et al. (2020) were able to reach an understanding of how and why the variables were associated; thus, evaluate policies and practices related to intellectual and developmental disabilities. It

was also suggested for future research to use mediators and moderators in enhancing theory development as demonstrated in other previous studies (Cummins, 2005; Gómez et al., 2020; Karazsia and Berlin, 2018; Zuna et al., 2009).

The following discussions will clarify the emergence of the use of the terms moderators and mediators, and how they inform the current theory. The terms mediators and moderators, instead of stressors and influencing factors, are used only in this chapter to aid the description of the relationships in the substantive theory. The rest of the chapters include the expressions stressors and influencing factors to avoid inducing confusion in describing the stressors as mediators and influencing factors as moderators.

Figure 10. 1: Spider map for conceptualizing relationships between codes and categories

Colour coding: Child – Parents – Both

Children's behavioural and emotional reactions to stressful life events related to living with CHD

1) Relationship with CHD stressors

2) sociocultural & daily life stressors

3) Physical compromises sterssors

Going through treatment
- Quality time with parents
- To skip school
- Not scared not sad
- Happy
- anger issue & x-rays
- No feeling
- No one want to stay at hospital 6 days
- After
- waiting
- Before
- Scared
- Sad
- Sick and tired
- Happy to do surgery

Hospital visits
- Unaware of CHD
- Happy to visit hospital (even after surgeries)
- Scared when younger
- Loved the doctors

Awareness of CHD
- Unaware
  - Even with scar presence
  - Don't know why visit hospital
- Aware
  - But at some point deny it
- Others influences
  - Doctors' advice not to tell
  - Others
  - Parents
    - Hiding from kids and grand parents
    - Wish to hide but told the kids
    - Didn't know tell or not
    - Changed the subject
    - Misleading info
    - Telling their kids
    - When older
    - kids asked and told them
  - Only if severe case and surgery
- Hurt
  - Emotional/ psychological
  - Why?
- Protection from
  - Isolated from friends
  - Overthinking about CHD
  - Living like sick child
  - Low knowledge
    - Afraid to read
    - No resources
  - Children can't understand
  - Parents beliefs
  - CHD invisible + can't hurt (can't feel it)
  - Parental guilt in discipline
  - Strict fathers

Behaviour improve
- Getting older
- Post-surgery

Compensate limited activity
- Feeling sad and physical symptoms (tired) when playing
- Tired more than healthy kids
- so normal (Normalization)
- lazy kids

Chest scar
- Questioned (why?)
- Covering chest
- Don't talk about it
- Hiding
- Awareness

Immigration
- Delayed treatment
- Delayed schooling
- linked to CHD

Learning & speech issues
- Crying + using sickness

Schooling
- Fathers: strict schooling
- Expectation
- +ve behaviour
- Denial

Sharing news with others
- Selective
  - Some friends
  - Some info
  - Only excited news
- Hiding
- Arab culture

Friendship
- Common traits
- Want friend CHD kids
- Bad Experience
- Laughing at him
- Turned down
- No similar CHD kids
- Don't Want friend CHD kids
- To get what wanted
- Angry cry scared when play
- Friends give special treatment

Family relationship
- Value of playing together
- Soft hearted /Caring
- Strong mother-child bond
- Siblings jealousy
- Comparisons

Death family
- Preferable treatment

Parenting
- Mercy sick child
- Kids asked
- Using sickness
- also grand parents
- Parents no like

Figure 10. 2: Flow chart of the proposed substantive theory

```
┌─────────────────────────────────┐        ┌──────────────────────────────────┐
│  Children (4-10 years old)      │        │  Exemplar story:                 │
│  with CHD                       │        │                                  │
└─────────────────────────────────┘        │  A six-year-old girl with CHD    │
              │                             │           ↓                      │
              ▼                             │  She underwent heart surgeries,  │
┌─────────────────────────────────┐        │  hospital admission, she didn't  │
│  Facing stressors when living   │        │  want to tell her friends and    │
│  with CHD (mediators):          │        │  school about her being sick,    │
│  - CHD medical treatment        │        │  she is usually absent from      │
│    stressors                    │        │  school because of frequent      │
│  - Sociocultural stressors      │        │  hospital visits, and she has a  │
│  -Physical changes stressos     │        │  chest scar from the surgery     │
└─────────────────────────────────┘        │  and is usually get tired when   │
              │                             │  running.                        │
              ▼                             │           ↓                      │
┌──────────────────┐   ┌───────────────┐   │  She is partially aware of her   │
│ Children's       │   │ Moderators of │   │  CHD, as her parents did not     │
│ awareness of CHD │   │ the strengths │   │  wish to tell her or the school  │
└──────────────────┘   │ and directions│   │  about it. She has a speech      │
┌──────────────────┐   │ of children's │   │  difficulty, which has led to    │
│ Parenting a      │   │ behaviour and │   │  delays in learning. Her family  │
│ child with CHD   │   │ emotions:     │   │  immigrated to Saudi Arabia,     │
└──────────────────┘   └───────────────┘   │  which caused delays in          │
┌──────────────────┐           │           │  receiving treatment.            │
│ Speech and       │           ▼           │           ↓                      │
│ recall issues    │   ┌───────────────┐   │  Her reactions were feeling      │
└──────────────────┘   │ Behavioural   │   │  sick and tired, but happy to    │
┌──────────────────┐   │ and emotional │   │  be finished with the surgery.   │
│ Family's         │   │ reactions     │   │  She gets angry and cries when   │
│ immigration      │   └───────────────┘   │  friends don't understand why    │
└──────────────────┘                       │  she is tired from playing. She  │
                                           │  feels different from friends as │
                                           │  she noted her chest scar; thus, │
                                           │  she's covered it and pretends   │
                                           │  she never saw it.               │
                                           └──────────────────────────────────┘
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10.3 The mediators

This study found that there are three stressors: the sub-categories to the main category, faced by children with CHD. During the analysis and conceptualisation stage, the researcher identified an emerging theoretical proposition that these stressors acted as mediators explaining the relationship between having CHD and changes in the child's behaviour and emotions. Mediators describe the relationship between two variables and explain how a variable can facilitate an outcome variable (Holmbeck, 1997; Tsang, 2015). As a variable can provoke changes on another variable, a mediator plays an intervening role that supports the influencing effect between the two variables (Tsang, 2015). In other words, in the current study, children with CHD faced stressors, which act as mediators that influence their behavioural and emotional reactions. Figure 10.3 demonstrate the stressors' mediating relationship between a child with CHD and their behavioural and emotional reactions.

In this proposed theory, the mediating stressors were found evident in all the children with CHD, which means all children in this study faced all three types of stressors. Next is a brief description of the three stressors as mediators.

Figure 10. 3: The mediating relationship in the substantive theory
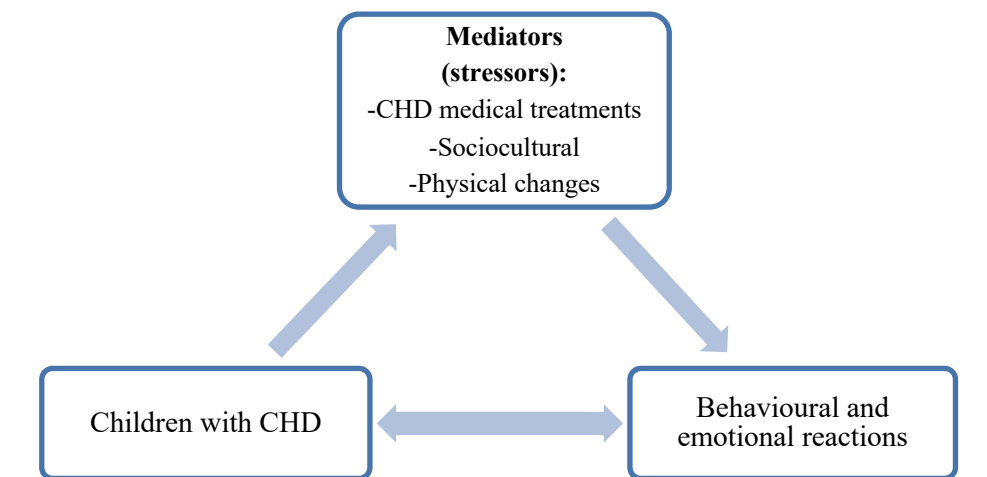
Mediator 1: CHD medical treatment stressors:

This theory suggests that the *CHD medical treatment stressors* is a mediator for children's behavioural and emotional reactions to living with CHD. As presented in the findings' chapters, children in this study dealt with the stress of pre-operative preparation, hospital admissions, surgical operation/ catheterisation, and follow-up after surgery. Relatedly, they exhibited some behavioural and emotional reactions. An exemplar story from the findings to demonstrate how *CHD medical treatments* mediated the behavioural and emotional reactions of children with CHD is provided below:

Exemplar vignette for mediator 1:

Kamal is a ten-year-old boy who was diagnosed with CHD immediately after birth. He had been regularly followed up by doctors since birth and recently was scheduled to undergo a heart surgery. Since then, he behaved excitedly about it and told his friends about the operation. However, when the researcher asked him what he felt about going into surgery, he reported his feeling of not wanting the surgery to be done.

Kamal faced the stress of going into a surgical operation, and this stress mediated his behavioural and emotional reactions. Although he seemed excited by telling his friends about the operation's news, he actually felt that he did not want the surgery to be done.

Mediator 2: Sociocultural stressors

Stressors from the sociocultural aspects of the child's life are suggested as another mediator for children's behavioural and emotional reactions. Children's interactions with family, friends, and school while living with CHD were identified as social stressors and linked to certain behavioural and emotional reactions in the children. Receiving preferential treatment from

family members because of having CHD and siblings' jealousy are two examples of social stress for the children. Since the jealousy feeling was induced by preferential treatment, it was suggested that when the relationship between children with CHD and their siblings was impacted, it led to worsening the jealousy between them and induced anger, and crying in children with CHD who also asked parents to shift their attention towards them (see Chapter 7, section 7.2). Schooling and friendships also acted as stressors for the children especially if the school did not know about the child having CHD. Thus, schooling and learning can be stressful while dealing with CHD and hospital visits. Also, friendship can be stressful, as a child with CHD doubts about getting tired when playing with friends, or telling their friends about their CHD.

Below is an exemplar vignette of a child participant reacted to *sociocultural stressors*.

Exemplar vignette for mediator 2:

Maher is a four and a half year old. He was described as quickly getting angry and crying. His mother reported him being angry if he did not get what he wanted, and his older sister used to get jealous of him because of that. The mother explained that she gave him special treatment and showed mercy for him because he was sick and her other children were normal. His mother also reported incidents where Maher were jealous of his sister when the mother attended her.

Maher's behavioural and emotional reactions of anger, crying, and jealousy were mediated by his relationship with his family, his parents' preferential treatment, and the jealousy of his sister.

Mediator 3: Physical changes stressors

Children with CHD would have limited physical activity levels and easily got tired, exhausted, breathless when running or playing, resulting from their restricted heart function and low oxygen saturation levels. These limitations induced reactions in the children such as feeling sad when easily getting tired and feeling different from others. Children faced the stress of dealing with this limited activity, especially at this young age where children want to run and play with friends. Therefore, *physical changes stressors* were found to be mediating children's behavioural and emotional reactions.

A physical change that children with CHD had is chest scars from heart surgery. This change caused reactions in the children in terms of questioning why they had a scar on their chest and why their siblings had no similar scar. They also felt different from others and hid their scars from others. An exemplar vignette is provided below showing one of the children in this study exhibiting behavioural and emotional reactions caused by *physical changes* mediator.

Exemplar vignette for Mediator 3:

Ali is a nine-year-old boy, loves to play football with his friends. However, he reported getting tired and becoming breathless with fast heartbeats when playing. He also said that he got tired more often than his friends, and he had to stop playing to get rest. Ali reported being sad about this, pointing at a sad emoji. Moreover, Ali was curious about the chest scar he had from heart surgery and asked his father about his brother not having the same scar.

Ali questioned his chest scar and felt sad and different from other healthy peers because of getting tired when playing. Ali's stress from the physical changes (getting more tired and having a scar) was mediated for his feelings of sadness and being different from others.

10.4 The moderators

This theory proposes that the four emergent influencing factors moderate children's reaction to the stressors. These are: the child's awareness of their CHD condition, the way parents are parenting their children, speech and recall issues or delays, and family's immigration (Figure 10.5). Moderators act on the relationship between two variables and defined as the factors that modify or influence the direction and strengths of the relationship between the variable and the outcome (Bhandari, 2021; Holmbeck, 1997; Tsang, 2015). For example, the moderators' roles in defining the strength and direction of the relationship are demonstrated in the current study when children with CHD who faced a sociocultural stressor (mediator), which involved their family's relationships, displayed reactions of being sad and jealous (outcome variable) when their parents showed preferential treatment to other siblings. The moderating effect here is parents which indicates that the stronger the parental preferential treatment the higher the sociocultural stress and the more

reactions of sadness and jealousy in children. Also, this theory suggested that not all influencing factors act as moderators for the children. For some children, all four moderators would be overlapping in influencing the way the children reacted to the stressors. Other children would have only one or two of the four moderators (such as awareness of CHD and parenting moderators) influencing their reactions to stressors (Figure 10.4). The next sections describe the four moderators and how it is proposed they contribute to children's reactions to stressors. They are followed by explanations of the relationships between each mediator and the moderators.

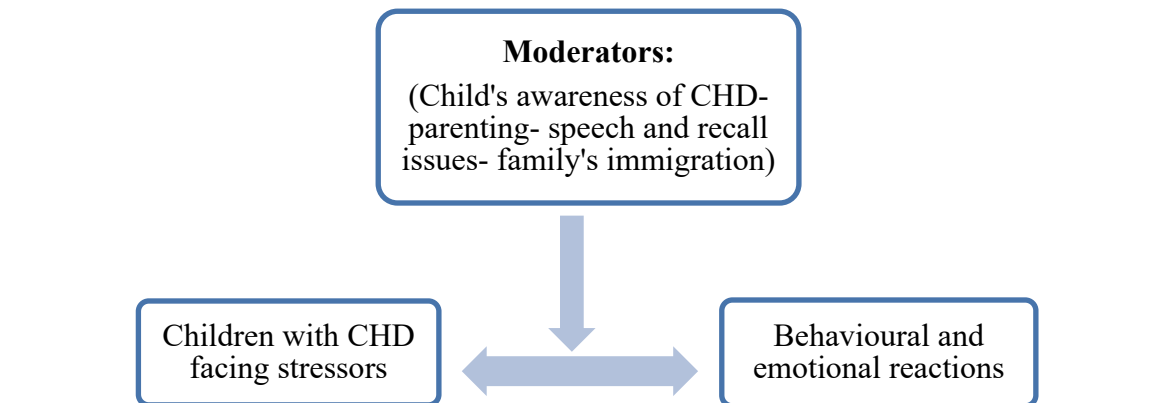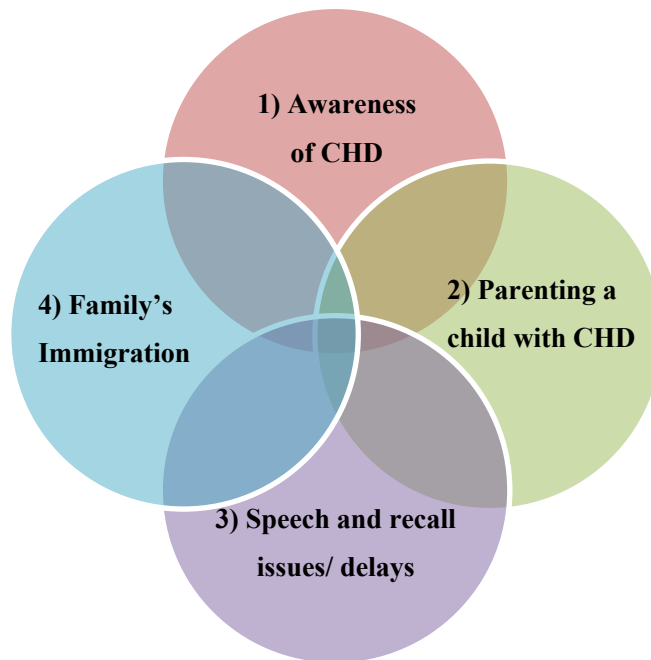**Figure 10. 4: The attribute of moderators in the proposed theory**

Figure 10. 5: Moderators in the proposed theory

Moderator 1: Child's awareness of CHD

Children with CHD, in this study, had different levels of awareness about their conditions. Some children were fully aware of their heart problems and the surgery they had undergone, while others were found lacking in awareness of their condition. Children's level of awareness of their condition moderated or influenced the way they reacted to stressors. For example, children who were unaware of their CHD did not understand why they got tired when playing. Therefore, they felt different from others and sad because they could not understand why they got tired. The mediator in this example is the physical changes stressor and the moderator is child's awareness of CHD.

Moderator 2: Parenting children with CHD

The factor of parents and parenting is a prominent moderator with most of the children in this study and found as an overarching moderator that links to the other moderators. In fact, parenting can be influencing the other moderators in

most cases. For example, parents wanted to keep their children unaware of their heart condition to protect them from emotional harm; thus this influenced children's lack of awareness about their CHD. Furthermore, parents may wish to avoid talking about their children's condition with others; they would also influence children and instruct them not to share the news of their condition with friends and others. The mediator in this example is sociocultural stressors which include sharing news of CHD with others, and the moderator is the parenting.

Moderator 3: Speech and recall issues/ delays

Speech and recall issues or delays were noted in the children in this study, and are also suggested as moderating the way the children with CHD reacted to stressors. Some children demonstrated issues such as unclear pronunciation of words, or recall difficulty which are unexpected at their milestone and developmental stage. These issues, delays, or difficulties were found to be significantly associated with the children's schooling. For example, children who experience speech issues have their schooling impacted; thus, they could dislike going to school as they felt learning could be stressful with the speech issue. The moderator in this case is the speech issue and the mediator is the sociocultural stressors, which include schooling.

Moderator 4: Family' immigration

In this study, there were two immigrant families who left their countries to seek proper medical treatment for their children with CHD in Saudi Arabia (SA). Thus, family immigration acted as moderators for only two of the children in this study. According to Holmbeck (1997), the moderators may or may not have a moderating association with all or some of the study concepts, which means not all moderators must serve an influencing association for all of the children in the current study. In addition, it was found that the immigration process had an exceptional and vital influence on these two

children and their reactions to stressors; therefore, it was important to address the immigration as a moderator to understand their behavioural and emotional reactions.

Children of immigrant families experienced delays in accessing medical care and proper management for the child's condition. Also, in the process of immigration, these children had experienced delays in school's admissions which influenced their behavioural and emotional reactions towards schooling as part of *sociocultural stressors*. Moreover, it was observed, during the interviews, that children of immigrant families showed speech issues, difficulty in recalling things which caused delays in their schooling, and retaking grades. From these examples, it was proposed that family's immigration is a moderator, and the *CHD medical treatment* and *sociocultural stressors* are the mediators for their behavioural and emotional reactions.

The following section of this chapter will present the interrelatedness between mediators and moderators demonstrating children's behavioural and emotional reactions as mediated by the stressor and moderated by the influencing factors.

10.5 Relationships between the mediators and moderators

The distinction between mediators and moderators is that mediators explain the mechanism of how two variables are related; while the moderators are factors impacting the strength and direction of the relationships between the two variables (Bhandari, 2021). This section describes how this theory proposed relationships between the mediators and moderators and that one or more of the four moderators influenced children's reactions to the mediators. The relationship between the mediator *CHD medical treatment stressor*s and the moderators is illustrated in Figure 10.6. These stressors included the child undergoing two phases of their CHD treatment journeys: Going through *CHD correcting procedures* and *hospital admissions or visits* for regular check-ups. All moderators (awareness, parenting, speech and recall issues/ delays, and family immigration) were found, jointly or separately, to influence the

mediating relationship between having CHD and children's reactions to CHD medical treatment stressors (Figure 10.6). An exemplar vignette from the findings of how one or more moderators influenced the children with CHD when facing the CHD medical treatment is provided below.

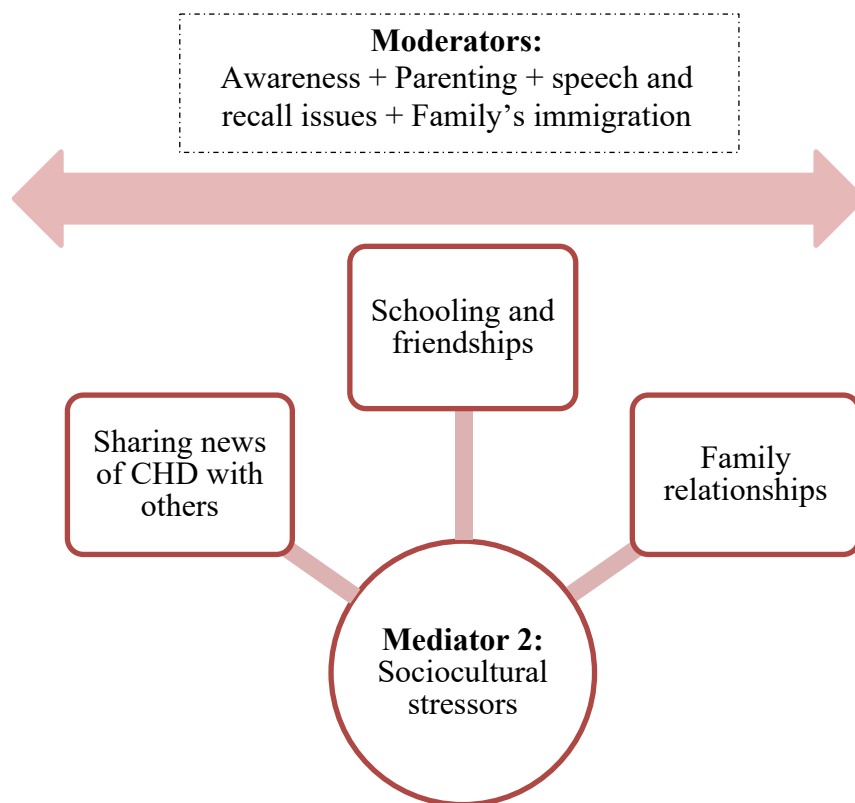**Figure 10. 6: Relationship between moderators and mediator 1**
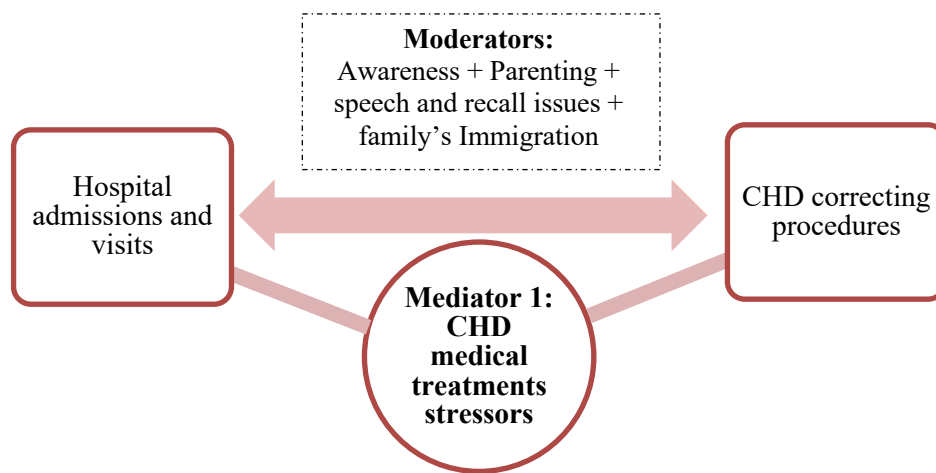
Exemplar vignette of relationship between moderators and mediator 1:

Leen is an six-year-old girl who had a severe type of CHD and had undergone a surgical operation and two cardiac catheterizations. She was diagnosed immediately after birth, but her medical treatments were delayed until she was three years old because her family had to emigrate from their country to Saudi Arabia to seek reliable medical care. Her father described her traumatic experience when she was admitted to the ICU, and she used to cry and get angry. Her father described he had difficulty to keep recalling her having CHD before her surgery was performed. However, at the time of the interview she demonstrated an awareness of her condition and she reported her happy feeling when visiting the hospital after the surgery was completed.

Leen's CHD medical treatment was influenced by the moderators of immigration which caused delays in receiving treatment at the optimum time. Her father also reported her low awareness of her condition which suggested as another moderator that can relate to her anger and crying reactions when she was admitted in the ICU which subsided after the surgery was done and transformed into feeling of happiness.

Moreover, the relationship between the moderators and mediator 2 *sociocultural stressors*, included *family's relationships, school, friendships*, and the child's willingness to *share news of CHD* or information about their conditions with others, as demonstrated in Figure 10.7. It was identified in theorizing the findings that all moderators can influence the children when facing sociocultural stressors.

Figure 10. 7: Relationship between moderators and mediator 2

An exemplar story from the findings is provided to demonstrate the proposed relationship between moderators and mediator 2,
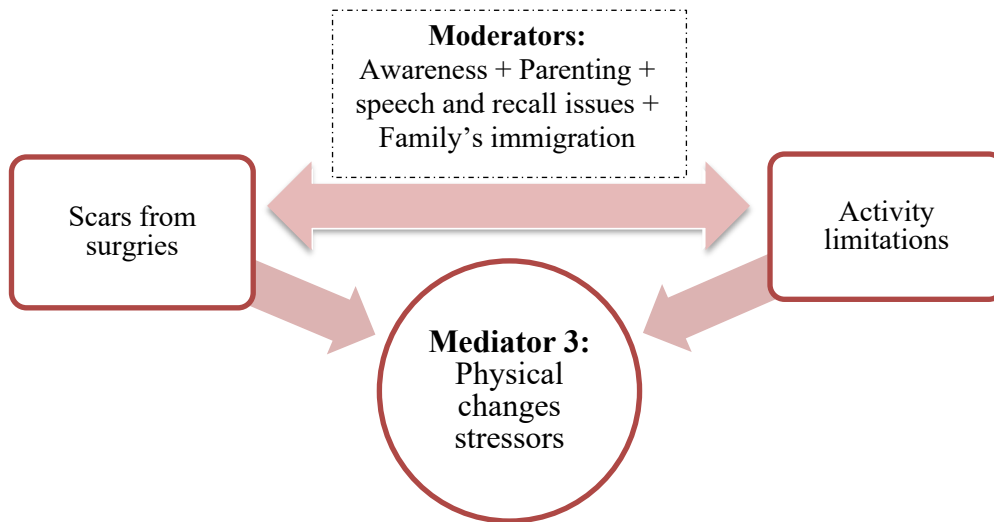

Exemplar vignette of direction between moderators and mediator 2:

Sara is an eight-year-old girl. She is a child of an immigrant family who left their country to seek medical treatments in SA. She was reported with anger and crying issues by her father. Sara's father did not want to describe the condition to her as he believed that she would not understand if he talked to her about her condition. Her parents also did not tell their friends and family about Sara's condition. However, in her interview, she was aware of her condition. Sara usually got tired when playing with sisters and friends. Her friends did not know her condition and her anger issues and, as described by her father, she got into fights at school. Sara's schooling was impacted as she had to retake grade two because of her recall and pronunciation issues. Her father reported him being strict with Sara when she failed at school. He also mentioned his doubts that Sara's recall issue might be related to her CHD condition.

Sara's schooling and friendships, which are concepts in sociocultural stressors, were influenced by the moderators: awareness of CHD, immigration, parenting, and speech issues, causing her behavioural and emotional reactions of getting angry, and crying.

Furthermore, Mediator 3 in this study is about children with CHD facing stressors of *physical changes*, and the changes include *physical activity limitations* and the presence of a *chest scar from heart surgery*. A demonstration of the relationship between moderators and the mediator 3 is presented in Figure 10.8. An exemplar story from the findings is also provided.

Figure 10. 8: Relationship between moderators and mediator 3

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                    ┌ ─ ─ ─ ─ ─ ─ ─ ─ ─ ─ ─ ┐
                    │      Moderators:       │
                    │  Awareness + Parenting +│
                    │  speech and recall issues +│
                    │   Family's immigration │
                    └ ─ ─ ─ ─ ─ ─ ─ ─ ─ ─ ─ ┘

    ┌───────────┐                              ┌───────────┐
    │ Scars from│  ◄══════════════════════►    │ Activity  │
    │  surgries │                              │limitations│
    └───────────┘                              └───────────┘
            ╲                              ╱
             ╲        ┌──────────┐        ╱
              ╲       │Mediator 3:│      ╱
               ►      │ Physical  │    ◄
                      │  changes  │
                      │ stressors │
                      └──────────┘
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Exemplar vignette of direction between moderator and mediator 3:

Mohammed is a six-year-old boy. He reported himself being scared of getting hurt when playing with friends. This was also reported by his mother, as well as crying easily. Moreover, Mohammed's mother reported telling her son to cover his chest scar and not tell his friends about his condition to avoid being hurt by his friends. Mohammed demonstrated unawareness of the condition in his interview as his mother did not want him to know about the CHD and hurt his feelings.

Mohammed's reactions to physical activity limitation and presence of chest scar were influenced by the moderators of the child's awareness and parenting through the behaviour of hiding and covering the condition and the chest scar. Mohammed had also reported feeling fearful of getting hurt when playing with friends, which can relate to his mother warning him to hide his scar to avoid getting hurt.

10.6 Summary

This chapter described the generated substantive theory of *children's behavioural and emotional reactions towards stressors related to living with CHD with the presence of influencing factors.* The core category and main concern in this theory is *children's behavioural and emotional reactions as living with CHD.* The stressors, as sub-categories, that children with CHD faced, have mediating properties in this theory, which include *CHD medical treatment stressors, sociocultural and daily life stressors, physical changes stressors.* These mediators describe the relationship between the variable of children living CHD and their behavioural and emotional reactions. Moreover, this theory also identified the four influencing factors: child's awareness of CHD, parenting, speech and recall issues/ delays, and family's immigration as moderators for children's behavioural and emotional reactions. These moderated the way the way children reacted to stressors as living with CHD. Studying the relationship between mediators and moderators revealed that each type of mediator caused different behavioural and emotional reactions in children, with some or all of the moderators influencing these children's reactions.

Chapter 11 Discussion

11.1 Introduction

The chapter includes an overview of the study findings and discusses the contribution of this study to existing knowledge. Next, it explores the literature regarding stress associated with changes in behaviour and emotion in children with a long-term condition and the influencing factors. Discussion of the emergent theory against the existing literature is also addressed and finally, recommendations for future research, strengths and limitations are presented.

11.2 Overview of the study findings

This study aimed to explore the perceptions of children aged 4-10-years old with CHD in Saudi Arabia (SA), and their parents' proxy reports of the children's behaviour and emotions. Listening to young children's voices was the purpose of this research to provide them with the opportunity to explore their feelings and report their behaviours as they lived with CHD. Parents' proxy reports added a broader understanding to the children's self-perception of their behaviour and emotions.

To address the research aim and question, Charmaz's constructivist approach of GT was followed. Through in-depth semi-structured individual interviews, children with CHD and their parents reported behavioural and emotional changes. Further conceptualising and theorising following Charmaz's approach guided the generation of a substantive theory of *children's behavioural and emotional reactions towards stressors related to living with CHD with the presence of influencing factors.* The theory proposes that children with CHD faced stressors which mediate their behavioural and emotional reactions. These stressors were: CHD medical treatment stressors, sociocultural stressors, and physical changes derived from the analysis. Moreover, children's behavioural and emotional reactions to these stressors are moderated by four influencing factors: child's awareness of their CHD,

parents and parenting, child's speech and recall issues or delays, and the family's immigration.

11.3 Novel contribution of the current study

This study is the first to obtain the voices of young children (4-10 years old) in Saudi Arabia (SA) with CHD and their parents about the children's behaviour and emotions. Prior to this study, there was a gap in international knowledge regarding young children's own perceptions of their behaviour and emotion as related to CHD.

Moreover, this is believed to be the first time GT methodology was used and a substantive theory generated about the behaviour and emotion of young children with CHD. The insights gained from this substantive theory provides a foundation for other researchers to further explore views of children with other types of long-term conditions. This substantive theory not only provides an understanding of children's behaviour and emotions, but it also suggests relationships between having CHD and related stressors and influencing factors. This study suggests that there is a link between CHD and changes in behaviour and emotions among children with CHD in SA. The findings from this study provide insights about the risk of these behavioural and emotional changes impacting children's future health, developmental and learning, and social status. This study also provides the healthcare professional with insights into the impact of having CHD for children, thus supporting the development of care that may reduce the impact of CHD on children's behaviour and emotions. In addition, obtaining both children's and parents' perceptions, through interviews, facilitated a more comprehensive understanding of children's emotions and behaviour, which are considered original in the literature about the behaviour and emotion of children with CHD. Furthermore, the researcher used art-based approaches for children's interviews, which is the first time such an approach has been used in research with children in SA.

11.4 Contextualising stressors and influences on behavioural and emotional reactions in children with CHD in SA

The following discussion breaks down the main elements of the generated substantive theory, stressors and influencing factors and considers them in light of current literature.

A child can face several stressors from their usual daily life activities or interactions such as parental and societal pressure, school's expectations, friendships and peer pressure, moving house, body image changes, and physical activity limitations (Kaneshiro, 2021). These stressors in children have been associated with behavioural and emotional issues, such as fear, crying, and anger (Kaneshiro, 2021). These findings are also reflected in previous studies involving children with long-term conditions. Young children aged 3-5 year-olds with long-term conditions, including CHD, were at risk of developing depressive symptoms, and their illnesses were linked to their social impairments (Curtis and Luby, 2008). Moreover, a high risk of developing emotional and behavioural problems was demonstrated among children aged 7- 9 years old with long-term conditions compared to a healthy group of children (Hysing et al., 2009). Stress in children related to having long-term conditions is consistent with that reported in a recent meta-analysis by Pinquart (2020) who indicated that children with severe long-term conditions and who received intensive treatments showed high levels of post-traumatic stress symptoms (PTSS). Similar CHD related stressors were associated with children's behavioural and emotional reactions in the current study.

The stress of undergoing medical treatment and subsequent hospitalisations and follow up appointments was found to be associated with children's behavioural and emotional reactions. It is important to note that some children in the current study underwent two or more episodes of heart surgery and catheterisation events, while others only experienced a single surgery or catheterisation. Therefore, repeated surgical procedures suggest repeated

experiences of stress related behaviour and emotions. The findings from a recent review by Hu et al. (2020) highlighted the impact this can have. Some of the reviewed studies found that multiple surgical procedures for children and adolescents with CHD was associated with a greater risk of psychosocial issues such as withdrawn behaviour, anxiety, attention, and aggressive behaviour. However, the review also reported that few other studies revealed no association between the psychosocial issues and undergoing multiple heart surgeries in children who had their surgery as neonates; this was explained by Hu et al. (2020) suggesting that cognitive skills are not fully developed in neonates, and thus, no psychosocial issues were experienced by these children. Whilst the conflicted findings from the current study and previous studies regarding the association between surgical procedures and children's behavioural and emotional issues suggest other factors could have influenced the development of behaviour and emotional issues in children with CHD.

Feelings of being scared, sad, sick, and tired, pre-invasive procedures that subside post-intervention, have been identified in this study, and these also have featured in previous literature. Preoperative behavioural problems were reported in a previous review on young children with CHD aged 2- 3 years old, especially in severe cases, where there was a need for complicated surgical correction procedures at an early age (Johnson, 2015). A possible explanation for preoperative emotional and behavioural issues is that the heart condition would improve after the surgery; thus, children can experience improvement in disease symptoms and feel relieved of stress and, as a result, they would exhibit fewer behavioural and emotional problems. This was demonstrated in a study by Kumar et al. (2019) where 5-15 year olds with a range of CHD severities had lower stress and anxiety levels post-surgery than they had pre-surgery. The study assessed the children for psychological, stress, and anxiety parameters a day before their surgery and three days after, to provide a comparetive score of before and after surgery (Kumar et al., 2019). This finding is further iterated in a study conducted with children 5- 18 years

old with mild cases of CHD who were assessed before and after their CHD catheterisation procedures for their quality of life; they demonstrated gradual improvement in quality of life parameters, including emotional and social outcomes, six months after their catherterisation procedures (Sun et al., 2021).

However, these findings are contrary to the conclusions from Guan et al. (2014), in which children with CHD in China who had heart surgery and catheterisation at aged 1.5- 5 years old; these children were assessed after they had completed their heart surgery or catheterisation procedures at age 6-13 years old and found to have behavioural problems such as social withdrawal, attention problems, depression, and aggressive behaviour. This, as also observed among some children in the current study, was related to the child dealing with a chest scar after the surgery and post-surgical pain, which made the children feel different from their peers and led to them excluding themselves from social activities (Guan et al., 2014). These conflicted findings, between the current study and the literature, raise questions regarding children's behavioural and emotional changes pre- and post- treatments. For instance, whether the stress of undergoing treatment diminishes afterwards, or transforms into another type of stress (e.g. chest scar and social stress). Answering these questions through future research will contribute to the suggested link in this substantive theory about children's stress related to CHD medical treatments and their behaviours and emotions.

Noticing a chest scar from surgery as a stress for children post operatively, was similar to what children in the current study showed through their behavioural and emotional reactions. The scar was a particular source of stress for children who questioned why they had these scars. They showed reactions such as sadness, frustrations, and compared themselves to healthy peers. Children with other types of chronic illnesses can also experience similar stress regarding the surgical scars. This is in accordance with another study of children with the birth defect of oesophageal atresia, who encountered having

surgical scars as a stressor and led them to adapt behavioural changes, which were recognised by Dellenmark-Blom et al. (2016) as coping strategies, e.g. avoidance or acceptance of the disease-related body changes.

Likewise, some children in the current study tried to hide and cover the scar as they were told to by their parents and chose not to talk about it; these parents wanted to protect their children from emotional harm and feeling different from others. Parents' protectiveness is discussed in section 11.4.2 in this chapter. To confirm the association between having a chest scar and emotional harm, the views of children and young adults with CHD were investigated in Korea. These children experienced being hurt by others' curiosity about their chest scars when they were undressed in traditional bathhouses; in turn, as a coping strategy, they wanted to avoid being in the bathhouses (Lee and Kim, 2012). In another study physical changes due to long-term condition were linked to adolescents being negatively affected by others' reactions to their physical appearance (Ferguson and Walker, 2014). Therefore, it seems possible that these children were looking to adopt coping strategies for the stress of having a chest scar. As some children wanted to cover their chest scar in the current study, it could suggest children's reduced ability to adapt well to CHD, resulting in feeling different or covering the chest.

Even after undergoing surgery, children in this current study reported that they loved visiting the hospital and seeing the doctors who performed their operation. These findings are consistent with those of a previous study, where children with acute and chronic illnesses aged 7-17 years old had positive views of their doctors after they experienced more than one day of hospitalisation (Coyne and Kirwan, 2012), reporting that hospital was a place where they go to be cured, and considering their doctors as friendly, kind and smart. However, other children in the same study, who were awaiting surgery, reported negative feelings toward the hospital as they regarded it as a scary and horrible place, and wanted to be better prepared for hospitalisation, be told

about the operation, and receive answers to their questions from doctors and nurses (Coyne and Kirwan, 2012). The inconsistency in children's perceptions of the hospitals and doctors could be due to inadequate coping in children, related to being less prepared for hospitalisation and unaware of their conditions (Coyne, 2006; Coyne and Kirwan, 2012). The contribution of children's awareness to their stress level and behaviour and emotion is discussed in section 11.4.1 in this chapter.

This substantive theory also suggests that the stress from children's interactions with family relationships, friendships, schooling, and telling others about their condition provoked emotional reactions like anger and jealousy, and behavioural reactions like crying and fighting with peers. Despite the siblings fights and jealousy reported by children with CHD and their parents, strong relationships and parental attachment were found between children and their family in this current study. Children demonstrated their love and admiration for parents and family by drawing hearts next to the picture of their family members. An advantage of this strong attachment was demonstrated by a previous study, which indicated that parental attachment could promote parents' and children's coping with CHD, and contribute to children's better health outcomes and lower parental anxiety (Jackson et al., 2015). Close relationships of the children with CHD with their siblings were also reported by Knecht et al. (2015), where siblings of children with long-term conditions had a strong bond with their sick brother or sister. Moreover, in the current study, empathy and caring about family members were common traits of children with CHD when anyone was in pain, crying or feeling sick, as reported by parents. The empathy of children with CHD to siblings and parents was demonstrated through them taking care of a sick sibling or crying when someone else cries. Consistent with the literature, it was found that children with long-term conditions, compared to healthy children, can develop a higher level of empathy traits in response to being exposed to sickness and meeting other patients at hospitals (Sterling and Friedman, 1996).

Likewise, it was found that siblings of children with a long-term condition developed empathy toward their sick brother or sister as they grew up witnessing their sickness and assisting in their care (Knecht et al., 2015), which was also found among parents and siblings of some children with CHD in the current study. This can suggest a shared empathy between the child with CHD and their family members. It can also be suggested that children with CHD, because they experienced hospitalisation and sickness, did not want their family members to experience similar hard times; thus, they felt sorry for them, cried, and took care of them. One possible explanation for children's empathy is living in an empathetic environment where parents' empathy can foster empathic traits in their children from an early age (Levy et al., 2019).

Children's friendships in this study were described as being angry and fighting with friends at school in order to get their own way when playing or in fear of being hurt, which is proposed as a stressor for the children in this substantive theory. One explanation of this behaviour would be that their friends mistreated them, teased them or fought with them, as some children report in this study, which suggested a level of bullying or peer victimisation. A previous literature review by Sentenac et al. (2012) found that peer victimisation is common among children with long-term conditions, especially those with learning disabilities or language issues. These findings contribute to school's settings and families, and the need for them be aware that children with CHD are prone to peer victimisation or bullying. Also, this indicates that children need adequate support to avoid the risk of developing social anxiety and depression, which are associated with children with long-term conditions (Sentenac et al., 2012).

Even though children in this study faced stress when dealing with their physical changes related to CHD, they did not hesitate to be physically active and to enjoy being active, even when they experienced tiredness and breathlessness. This finding corroborates the findings in a previous study by

Blais et al. (2020), in which children with CHD felt encouraged to engage in physical activities, join activities with friends and enjoy their success of participating in physical activities such as winning a sports game; thus, this enhanced their feelings of belonging with their friends (Bjorbaekmo and Engelsrud, 2008). Gannoni and Shute (2010) also reported that children with long-term conditions were frustrated about adhering to the routines of treatment, taking medications and dietary restrictions, which limited their involvement in social and physical activities with friends (Gannoni and Shute, 2010). Thus, it can be explained that setting restrictions for children's activity can emphasise children's feeling of being different from others and negatively impact their emotional wellbeing (Kolt et al., 2020). On the contrary, it was found that exercise with appropriate medical guidelines can improve emotional quality in children with CHD (Kolt et al., 2020). Feeling different from friends at schools was also demonstrated in the current study when they felt tired more frequently than their healthy peers.

Children's friendships and playing with friends at schools are essential for their psychosocial development. Children in this study, according to Erikson's psychosocial development theory, are in the stages of play and school-age periods; thus, for their social development they need to have regular school days and contacts with friends to learn through play, get a sense of belonging and feeling of accomplishment (Erikson, 1993; Orenstein and Lewis, 2020). Children in the current study had to be absent from school during the days of hospital visits and surgical operations. Similar findings were also reported in a previous review by Lum et al. (2017), who identified that in addition to frequent absenteeism associated with the severity of long-term conditions, the children felt stress of trying to re-engage with the friends and catch up with school work when returning back to school after a period of absenteeism. Moreover, Im et al. (2017) found that low school adjustment among children with CHD was related to not telling their friends about CHD. These children demonstrated challenges when adjusting to school as they reached high

schools and not disclosing their conditions with others; thus, they were unable to develop close friendships (Im et al., 2017).

Sharing the diagnosis and experiences of CHD with family and friends was a sociocultural stressor for children in this study, which seemed to be strongly influenced by children's level of awareness of CHD. Some children were selective in who they told about their CHD in their friendship group, sharing only information about their conditions or sharing only some information about their condition. It was notable that if children were aware of their condition, they had the chance to decide whether or not they wanted to share the news of their CHD with others and plan their social interactions accordingly. So, in this study, children who were aware of their condition faced the stress of what and who to tell about their condition. This interpretation reflects what was identified in previous research where young children with long-term conditions such as oesophageal atresia aged 8-17 years old, and diabetes, nephrotic syndrome, sickle cell anaemia aged 3-11 years old and, found telling others about their conditions a stressful situation (Christie et al., 2012; Dellenmark-Blom et al., 2016). Disclosure of having a condition was considered a burden for children as they found it difficult to decide how much information they needed to share with others (Christie et al., 2012). Telling others about their condition was viewed as a stressful situation related to children's resolving a balance between the fear of being treated differently by others against the gain of others' adjustments to their conditions (Svensson et al., 2020). These children aged 5-18 years old felt the need to constantly remind their peers about their conditions because CHD is "invisible" and others cannot see it physically. At the same time, these children wanted others to perceive them as "normal", demonstrating their uncertainty regarding what to tell others about the CHD and whom to tell (Svensson et al., 2020).

Kendall et al. (2003) demonstrated that appearing physically "normal" or acceptable caused others to forget about the children's condition, which is considered an issue for children with CHD, who wanted to keep others aware of their conditions. Hence, children showed indecision regarding whom and what to tell about the CHD, which had also provided an insight into physical changes stressors. A previous study by Bjorbaekmo and Engelsrud (2008) studied physical movements during play and other activities in children with CHD. This study found that children showed uncertainty in their desire for others to consider their physical limitations, but, at the same time, they did not like others to be aware of their limitations (Bjorbaekmo and Engelsrud, 2008). Uncertainty in children's disclosure of CHD can suggest their need for support from families and healthcare providers in sharing information with others. In the review by Chong et al. (2018), children and adolescents with CHD aged 0-21 years old dealt and coped better with the stress and anxiety related to CHD and felt more normal when they received support from family and peers.

It is noteworthy that Arab cultural beliefs can influence children's sharing of their condition with others. Understanding the child's culture and background would help articulate why the children did not want to tell others about their condition. The Arab culture appreciates privacy and keeping private news, such as sickness, from others. As families and parents tend to hide this information from their children and others, they had also influenced their children to hide such information. Arab cultural beliefs of privacy is suggested to also explain the reason for parents not discussing the condition with children. The value of privacy can also culturally influence doctors which explains a doctor's advice to parents in the current study not to talk about the condition with children. Thus, the stressful situation of children's and families' decisions about sharing information of CHD with others can be implied by the beliefs of the Arab culture. These interpretations and observations are consistent with a previous study conducted in Saudi Arabia by Almesned et al. (2013), which found that the social and emotional stress

were significantly higher in families of children with CHD in Saudi Arabia, especially for those who underwent surgical procedures. However, despite this promising finding of Saudi Arabian culture, questions remained unanswered about why these families experienced a high level of stress and whether or not they had disclosed the CHD with others and with their children.

Despite the descriptions of children's emotional and behavioural changes related to stress in previous literature, several external factors are suggested to influence the extent of these behavioural and emotional changes. The factors proposed in the current study are discussed next in relation to the literature.

11.4.1 Children's awareness of CHD influencing their behavioural and emotional reactions to stressors

It was noticed in the current study that low awareness of their condition can make dealing with the stress related to CHD, e.g. physical changes, difficult for children with CHD; thus, they experienced negative emotional and behavioural reactions. This observation aligns with the findings of study by Lee and Kim (2012), where children and young adults with chronic conditions demonstrated feeling different and isolated from others when they were unaware of their conditions. These children did not discover their condition until they noticed their restricted activity level at school and their parents' protective behaviour compared to parents of healthy children. These children reported having more difficulty dealing with the condition when they were unaware than when they became aware of their conditions (Lee and Kim, 2012). Similarly, in this study, some children's awareness was linked with them noticing changes in their physical appearance (e.g. chest scar) or their grandparents treating them preferably; thus, they questioned their parents, who then explained the CHD to them. This suggests that children kept wondering about physical changes until they identified with their conditions as an older child which could lead to behavioural and emotional reactions at a young age.

One advantage of children being aware of their conditions, as noted in the current study, is that they were able to report their feelings and behaviour toward the stressors. However, children who had low awareness were less able to understand their feelings or behavioural reactions towards the disease-related stressors (such as having undergone treatment at a younger age). This is similar to a previous review which found that children with low awareness of their long-term conditions were less able to perceive the traumatic events related to their conditions than the aware children (Pinquart, 2020). Children's awareness of their CHD is important because it contributes to their ability to cope with stressors, thus decreasing the impact on behaviour and emotions. It was also found that children's awareness of their birth defect conditions can help them develop positive coping and adaptation strategies at a young age (Dellenmark-Blom et al., 2016; Gannoni and Shute, 2010). Moreover, children who knew about their condition learned coping strategies relating to their condition early, and discovered how to pursue or receive help and support from parents and others (Dellenmark-Blom et al., 2016). Another study demonstrated that informing children about their illness and the painful procedures, including surgeries, could minimize children's fear and anxiety during hospitalisation (Boztepe et al., 2017). These findings validate the importance of children being aware of their chronic conditions and thus able to cope better with them, and experience less behavioural and emotional issues.

Another advantage of the child's awareness of CHD is the link of awareness to reaching normalisation as a coping strategy. In a previous study by Ferguson and Walker (2014), feeling in control of the health-related challenges was noted in children who were aware of their conditions; this control was attained through perceiving themselves living everyday lives. These children described how they achieved normalcy by keeping the idea of having a chronic illness in the background while focusing on their other life events. Reaching normalcy or normalisation contributed to children's improved coping and dealing positively with disease-related stressors, thus experiencing less behavioural

and emotional problems (Ferguson and Walker, 2014). In contrast, children in the current study did not perceive themselves as normal which might be due to their low level of awareness of CHD; for example, they perceived themselves different than their healthy peers when they talked about their physical activity.

A main reason for children with CHD to be aware of their condition, is that they have the right to be informed about something concerning them. The UNICEF (1989) regulation of every child's right to be heard, stated that understanding their health condition's needs would help the children alleviate anxiety, enhance coping with the existing health condition, and gradually reach to the ability to make decisions about their health. Parents are to provide the appropriate guidance and information regarding their health condition; also, health professionals should use age-appropriate language, suitable for children's understanding capacity and create a friendly environment, so the child feels encouraged to ask questions (Lansdown, 2011).

However, it is recognised that cultural challenges could be encountered when adopting the suggestions of discussing CHD with the children in SA. Arab cultural beliefs could have an influence on children's awareness of CHD in this study, as it is recognised among Arab families that young children are not involved in discussion of health issues or related decisions, believing that children are less able to comprehend such information. Some parental perceptions in the current study represent these cultural beliefs which as discussed next in this chapter.

Children's awareness and cognitive abilities

Children's awareness of CHD contributed to how much and what they can understand about their conditions. The ability for the children to understand medically related information relies on children's language, and memory to comprehend disease's or medical treatments information (Grootens-Wiegers et

al., 2017). Parents in the current study had a significant influence on children's awareness, as most of them either concealed having CHD from their children or regretted discussing the condition with their children after explaining it to the child. Indeed, parents reported that they believed young children cannot understand health-related and medical treatments information because of their undeveloped thinking process; therefore, they did not explain the condition to their children. Nevertheless, children's cognitive and developmental stages link to their understanding of body parts or diseases, thus helping them be aware of their conditions. According to Piaget's cognitive theory, the age group of children in this study falls between pre-operational (2-7 years old) and concrete operational (7-11 years old) stages. In these two stages, children start to use language more maturely, their memory develops, and they start moving from non-logical thinking towards concrete and operational thinking (Huitt and Hummel, 2003). Relying on Piaget's theory, children can gradually learn and comprehend knowledge by using age-appropriate tools (Piaget, 1964), such as location and functions of body parts and the presence of issues with any body parts. As parents' beliefs of children's cognitive skills can strongly influence children's awareness of their CHD, it is suggested that an increase in the awareness of parents about the normal process of children's developmental stages and thinking process could help them to explain such information to their children. Nevertheless, cultural beliefs can be a barrier in achieving the goal of enhancing children's awareness of CHD in SA. Yet, it is suggested that with an adequate education and awareness, parents can learn to modify their beliefs as they understand the benefits to their children of being aware of the CHD.

Children's understanding of their health condition was explored by Bray et al. (2019). Children showed interest in knowing about the medical procedures they were undergoing, and they demonstrated understanding of health-related information, as images and simple language were implemented when explained to children. Furthermore, children's anxiety and uncertainty before

procedures were managed when they understood the procedures properly (Bray et al., 2019). These findings lead to a recommendation for future research to explore what the educational needs of children with CHD and their families are regarding CHD, and what the facilitators and barriers are to enhancing children's awareness about their conditions.

Children's awareness of CHD relates to low parental knowledge about CHD

Lack of parental knowledge about CHD might impact their decisions to discuss CHD with their children. Less knowledge about the CHD was an observation interpreted from parents reporting being unable to find available information resources about CHD, and many were noted to have minimal knowledge about CHD. Thus, the researcher in this study proposes that lack of parental knowledge is linked to their inability or unwillingness to talk about CHD with their children. This was also found by Kilicarslan-Toruner and Akgun-Citak (2013), in which parents reported their needs for detailed information about their children's long-term condition (cancer) from the doctors and nurses throughout the treatment journey, not just at the time of the diagnosis. The parents had difficulty finding sufficient information and pursued the internet or asked friends to learn more about the condition (Kilicarslan-Toruner and Akgun-Citak, 2013). It is suggested that lack of sufficient knowledge about CHD and low awareness might cause the parents to feel uncertain or less confident about what and how to explain to their children about CHD, as in current study, they expressed doubts about whether to talk to their children about the CHD or not. This was also reported by Alsaigh and Coyne (2019) in studying the experiences of mothers of children with growth hormone therapy. The mothers expressed uncertainty because of their limited knowledge, which made it difficult for them to manage the needs of their children's conditions and thus increased their stress and anxiety levels (Alsaigh and Coyne, 2019). Additionally, uncertainty of some parents in the

current study about seeking information about their child's condition was reflected in their avoidance of reading about CHD, thinking that knowing more about the condition would cause them emotional exhaustion. This highlights a need for increasing parents' awareness, and it is recommended that healthcare providers assess parents' needs for learning concerning their children's healthcare, including identifying types of knowledge needed and ways of learning (Nightingale et al., 2015).

Increasing the level of parental awareness would relieve parental stress and them being able to provide support to their children with CHD. Furthermore, this study recommends the establishment of good communication between healthcare providers and parents to enhance parents' awareness of their children's conditions. This recommendation is consistent with the previous study, which found medical staff's open communication with mothers of children with long-term conditions is significant for increasing mothers' awareness of their children's condition and promoting trust between mothers and medical staff, hence, enhancing maternal coping with a child's condition (Swallow and Jacoby, 2001). As primary caregivers for children with CHD, it is rational for parents to get proper support to cope well and adopt adequate parenting skills and support for their children. Future research is required to investigate possible challenges and barriers to the application of these practice recommendations.

11.4.2 Parental influence on the behavioural and emotional reactions of children with CHD

Parental protectiveness and normalisation

One reason for parents not discussing CHD with their children was the parents' protective feelings of their children and normalisation of their children's condition, which were not reported directly by parents or children. However, it was concluded from the researcher's notes, memos and

interpretations of parents' desire to hide information from their children and others. Previous studies had identified that the level of parental protectiveness could be increased according to the child's disease severity (e.g. birth defects) and vulnerability, especially when it combined a developmental delay (Laing et al., 2010). Accordingly, perceiving their children as "normal" and wanting them to live normal everyday lives, was also resonant within some parents in the current study. This observation has brought insight into parents' normalisation of their children's condition. Parents in previous studies also tried to normalise their children's long-term conditions and desire for their children to live as "normal a life" as possible (Williams et al., 2019). An example from the current study, is that some parents described their children as physically normal when playing and running with friends, even though they perceive themselves as quickly getting tired. Parents' normalisation of their children's condition can also be recognised as a positive coping mechanism which contributes to a better family functioning as it was found among parents of children with illnesses and who were dependent on medical devices such as mechanical ventilators (Toly et al., 2012).

Parents' protectiveness of their children's physical activity was demonstrated when they regarded them as lazy, perceiving them as not wanting to play actively or run like other children, even though these children actually loved to be physically active and were following their parents' instructions of not to play aggressively. Indeed, this was explained by a previous study which found that parents of young children can sense the vulnerability of the children regarding their limited physical activities and perceive them as "weak", and therefore, they feel protective of their young children (Ruggiero et al., 2018). Feeling protective of their children is believed to be linked to parents setting more restrictions for their children, which can negatively impact children's feelings of belonging to their peer group (Ruggiero et al., 2018). Parents in the current study were concerned about the deterioration of their children's heart condition; thus, they were instructed to avoid running and playing vigorously.

It can be suggested that if children understand their condition and symptoms of fast heart rate and low oxygen level, they can determine when and why to stop running and take a break.

Parents' protectiveness was also implicit by noting parents' cautiousness in telling others about their children's condition as they do not know how people would react to this news. This is consistent with parents in a previous study who wanted to protect their children's feelings, so they asked friends and family to treat them equally to other children (Rehm and Bradley, 2005). Therefore, in the current study, to hide the condition from their children, parents told their children misleading information or changed the subject whenever the children asked about things concerning their medical treatments, such as the reason for the hospital visits. As a result, the children's level of awareness of their condition was affected as discussed earlier.

The motive for parents' protectiveness and normalisation of their children with CHD, as explained by a previous study, was related to parental constant worries and stress about the CHD prognosis, managing medical appointments, and dealing with the unexpected news of needing surgery (Ong et al., 2011). Parents can be overwhelmed by these concerns while continuing parenting and supporting their children's needs throughout their treatment journey. Consequently, some parents informed the schools about the children's conditions. In contrast, other parents refused to notify the school, believing that teachers would treat their children differently and other children would hurt them. These findings from the current study concurs with findings from another study, where parents wished for a normal everyday life for their children with CHD and to be able to participate in activities; however, the parents showed some doubts about this wish since others tend to be over-protective of their sick children or keep forgetting about their condition and treat them inconsiderately (Kendall et al., 2003). Furthermore, parents in another previous study felt uncertain about the people's reactions when

knowing about their children's conditions and how they might treat their children (Rehm and Bradley, 2005).

It is vital to acknowledge that parenting a child with a long-term condition can be stressful for parents as they carry the primary responsibility for caring for their children's medical appointments, medication and to be vigilant all the time for any development of new symptoms (Morawska et al., 2015). This stress is linked to making such parental decisions and on the parenting styles for their children. Parenting styles are believed to be influential for children with long-term conditions and previous studies have shown that negative parenting styles have an association with children's behavioural and emotional problems (Crandell et al., 2018; Lundahl et al., 2006; Morawska et al., 2015). It is known that learning positive parenting, child-parent interaction, and stress reducing skills are important for parents of children with long-term conditions since they can prevent the development of child's behavioural and emotional problems (Lundahl et al., 2006; Morawska et al., 2015). Moreover, acknowledging parents' protectiveness and normalisation could aid healthcare providers to understand children's developing CHD-related stress or behavioural and emotional issues. Thus, through adequate psychosocial support, healthcare providers can help parents to learn to balance the protective feeling towards their sick child and the child's need to be informed about something concerning them (Coyne and Harder, 2011).

Parental favouritism of their child with CHD

Some parents treated their children with CHD preferably than the other siblings because they felt sorry about their condition and they worried that their children's heart condition would deteriorate. Previous literature has also demonstrated that as parents of children with long-term conditions perceive their children's vulnerability because of the sickness, their parenting styles would be impacted (Anthony et al., 2003; Mullins et al., 2007). Parents' preferable treatment for one child was identified by some studies in the

literature as "Parental Favouritism", where Bieber (1977) described that while the favourite child felt himself as unique and enjoyed the preferential treatment, the other siblings can feel inferior and become competitive and jealous of the favourite child which leads to tense and anxious sibling relationships (Bieber, 1977; Yahav, 2007). This finding also matches what was reported by a previous review by Deavin et al. (2018), indicating that jealousy was reported by siblings of children with long-term conditions because of the special treatment the parents granted to their children with illnesses (Deavin et al., 2018). Parents' favouritism is discussed here as it was a common parenting style noted among parents in this current study which impacted on children's relationship with siblings and, thus, demonstrated behavioural and emotional reactions.

Even though parents in the current study were already preferably treating children with CHD, the children felt jealous when parents attended to their other siblings, which led to more jealousy felt by the other siblings. Accordingly, children's feelings of jealousy imposed further negative related emotions and behaviour such as anger and easily crying in children with CHD and their siblings. This is consistent with previous research, which found that parental shift of responsibility, attention, and preferential treatment toward their child with chronic illness, can be associated with jealousy and negative impact on siblings' relationships (O'Haver, 2007; Rauer and Volling, 2007).

Findings from the current study and previous literature raise the importance of developing parenting styles suitable for a child with CHD to avoid disruption between the siblings' relationships and decrease negative emotions such as jealousy. An important recommendation for the future development in SA regarding parents of children with CHD, is to receive adequate psychosocial support about the positive parenting skills. Support group for parents with chronic illnesses can be reached via networking in social media in SA.

However, there is a need to establish a standardised support program for families of children with CHD launched by the Ministry of Health in SA. An example from other countries' application of parental support programs would be the Teen Triple P program, which is a well-known parenting program for parents of teenagers. This program provides support and education for parents aiming to enhance positive parenting skills to limit children's behavioural, emotional, and developmental issues (Sanders and Turner, 2019). The efficacy of this program was tested in many studies besides Steketee et al. (2021), who showed that with the implementation of Teen Triple P, parents had developed positive parenting skills, and lower parental stress and conflicts with children. It might be possible for similar programs to be adapted in SA, developed specifically for parents of children with CHD. This could also be useful for parents who have children with other long-term conditions. However, the application of such programs requires further understanding of its potential in SA. The principles of Teen Triple P program could be studied, and assessed against parents' needs and healthcare providers readiness in SA; it could then be modified to suit the Arab culture and adopted in SA.

11.4.3 Speech and recall issues associated with family immigration influencing behavioural and emotional reactions of children with CHD

Since some children in this study had speech and recall issues, it was crucial to understand the relationship between CHD and neurodevelopment or cognitive development in the literature for children with CHD. Brain development is essential for normal growth, development and learning. Developmental delay is considered high risk for children with CHD (Walker et al., 2012). Many studies have supported the existence of an association between CHD and neurodevelopmental delay in children (Gaynor et al., 2015; Nattel et al., 2017; Verrall et al., 2019). According to Erikson's stages of psychosocial development, the developmental stages of child participants in this study were

the play age stage of 3-5 years old and the school-age stage of 6-10 years old (Orenstein and Lewis, 2020). These developmental stages were considered when reviewing literature regarding the speech and recall status and learning difficulties of the children with CHD. Previous studies in children with CHD demonstrated the impact of developmental impairment on school performance (Hövels-Gürich, 2016; Sarrechia et al., 2016; Verrall et al., 2019), and neurodevelopmental issues were detected in 50% of the children in skills like language and communication, attention, social, and learning and mild cognitive impairment (Verrall et al., 2019). Moreover, neurodevelopmental issues such as memory, attention, and language skills impact the learning process and eventually schooling (Murphy et al., 2017; Sarrechia et al., 2016), and low school performance related to poor neurodevelopmental status were found in children with severe CHD types, who underwent surgeries and had prolonged hospitalisation (Sarrechia et al., 2016). These previous studies further confirm the association between schooling and learning difficulties and the speech and recall issues/ delays proposed in by the current substantive theory.

Previous literature has also shown a genetic association between CHD and the developmental problems in children, especially those with syndromic CHD (e.g. Down syndrome) (Nattel et al., 2017; Verrall et al., 2019; Walker et al., 2012). A review demonstrated that there are particular brain features in children with CHD, and some genes are found to affect the development of both heart and brain in isolated CHD (CHD, which is not combined with syndromes) and syndromic CHD (CHD combined with syndromes) (Nattel et al., 2017). The disease pathology and cardiovascular insufficiency in CHD can explain the effect on the brain and developmental problems. Oxygenation issues and hypoxic episodes in CHD cause alteration in brain blood flow and perfusion and contribute to brain development and neurodevelopmental disorders (Hövels-Gürich, 2016; Verrall et al., 2019). Thus, it is suggested that biological or genetic factors in children with CHD had caused the speech

delays and recall issues in the current study among children who did not get urgent medical care and suffered from cyanosis due to a low oxygen supply in the brain.

There is also a link found in the literature between CHD invasive treatment and the developmental issues in children. Several studies have reported that surgical interventions for children with CHD have been associated with children's developmental delays. The fact that most children with CHD, especially in moderate and severe cases, need surgical correction in their early life stage increases the risk for neurodevelopmental and cognitive developmental impairments (Gaynor et al., 2015; Murphy et al., 2017; Nattel et al., 2017). Neurodevelopmental problems were noted in infants who had undergone surgery when they reached one year old (Verrall et al., 2019; Walker et al., 2012). Furthermore, after undergoing surgery, the developmental issues identified for CHD children were language, attention, anxiety, depression, behavioural, fine motor, and cognitive skills (Nattel et al., 2017). According to these findings, it can infer that children with CHD are prone to develop developmental issues or delays such as, speech issues, since the relationship between CHD surgical interventions and developmental delays is well identified. Some children in this study, who had speech or recall issues, were also noted with delayed CHD treatment because of their family's immigration experience. This also accords with a previous study which found that the longer the child waited for the CHD correction surgery, the more brain damage could occur, leading to neurodevelopmental disorders (Nattel et al., 2017). These findings support the current substantive theory's suggestion that immigration can impose speech and recall issues in immigrant children, since receiving prompt treatment had not been met in cases of immigrant children in the current study.

Furthermore, speech issues such as stuttering and memory issues had caused stress in the children with CHD in dealing with these issues at school and

when communicating with others. Children demonstrated emotions like anger because their peers could not understand them when they were talking and teased their way of talking. Therefore, it can be suggested that speech and recall issues can negatively impact children's friendships and their emotional and behavioural reactions. Moreover, understanding when and how children with CHD can develop developmental delays would help increase the awareness of healthcare providers to respond with an early individual assessment for speech and memory issues and start early preventative measures. The struggles of immigrant families were extended due to poor socialisation, including school performance among immigrant children in the United States (Mirza et al., 2015). Schooling of many migrant children worldwide is delayed or disturbed because of the migration and travelling process (Pieloch et al., 2016). These findings agree with those observed in the current study, which showed that admitting to schools was delayed for the immigrant children either because of the immigration process or the speech and recall issues.

In the current study, an influencing relationship was found between family immigration and children's delays in receiving medical treatments. Thus, this substantive theory suggests that families' immigration circumstances have influenced children's behavioural and emotional reactions to the stressors of schooling, and CHD medical treatment. These children have gone through unique experiences compared to other children in this study, which could impact the way they deal with CHD related stressors. Also, it is noteworthy that children of refugee families usually do not choose to leave their country as they had to be led by their parents in this decision (Pieloch et al., 2016), which contributed to their experience of additional stress as they adapt and cope in the host country and with the idea of leaving their birth countries.

These families were immigrants from neighbouring Arab countries. They left their countries and came to SA to seek medical care for their children

diagnosed with CHD or still needing diagnostic procedures. The immigrant parents described delays in seeking medical care as the hospitals and clinics were unavailable because of the war; therefore, the diagnosis with CHD and receipt of treatment were delayed for years until they had immigrated to SA. Upon arrival in SA, families reported being confused about going through the health system and starting their children's treatments. Similarly, other parents in a previous study of Syrian refugee parents in the United States have reported difficulties communicating with the healthcare providers and managing their children's medical appointments, which caused delays in their children receiving medical treatment (Alwan et al., 2020; Pieloch et al., 2016). These findings also matched those of previous studies; a review by McKay (2019) demonstrates that immigrant children, who require medical care and treatment, have struggled to access healthcare facilities, and encountered strains in adapting to the host country's healthcare system (Kobylianskii et al., 2018; McKay, 2019). From these findings, it can be concluded that even after immigration, families remain to face difficulties in seeking medical care for their children, leading to further delays in receiving treatment as parents learn to adapt to the new health system in the host country. Early detection for speech and recall issues contributes to preventative procedures for all children with CHD. A strong recommendation was made for the need for prompt neurodevelopmental assessment of children with CHD to ensure early detection of any potential impairment (Hövels-Gürich, 2016; Walker et al., 2012).

Future research is recommended to explore the experiences of immigrant families of children with CHD in seeking medical care in SA. Previous studies have also highlighted the importance of understanding the cultural diversities among immigrant families (Kobylianskii et al., 2018) and determining the optimal way for immigrant children to access healthcare services (McKay, 2019). This could decrease the stress on children with CHD, which could be influenced by their families' immigration. Nevertheless, there is a need for

further investigations of the link between immigrant families in SA, developmental problems and prompt treatment for their children with CHD. Furthermore, further research is also recommended on investigating the friendships of children with CHD in SA and how this can impact their social related stress and behaviour and emotions. Additionally, future studies could address the impact of the physical restriction on children's sense of belonging with peers and their emotional and behavioural reactions in SA. Potential research work is also needed to explore the link between multiple invasive procedures and development of behavioural and emotional issues in children with illnesses. These future investigations will foster understandings of the impact of the multiple invasive procedures on the stress or behavioural and emotional issues in children and thus assist healthcare professionals to plan and apply preventative measures for the children in SA prior to their surgery.

The next sections include discussion of the emergent theory with other existing theories. Descriptions of similarities and differences between the current substantive theory and other existing theories are provided.
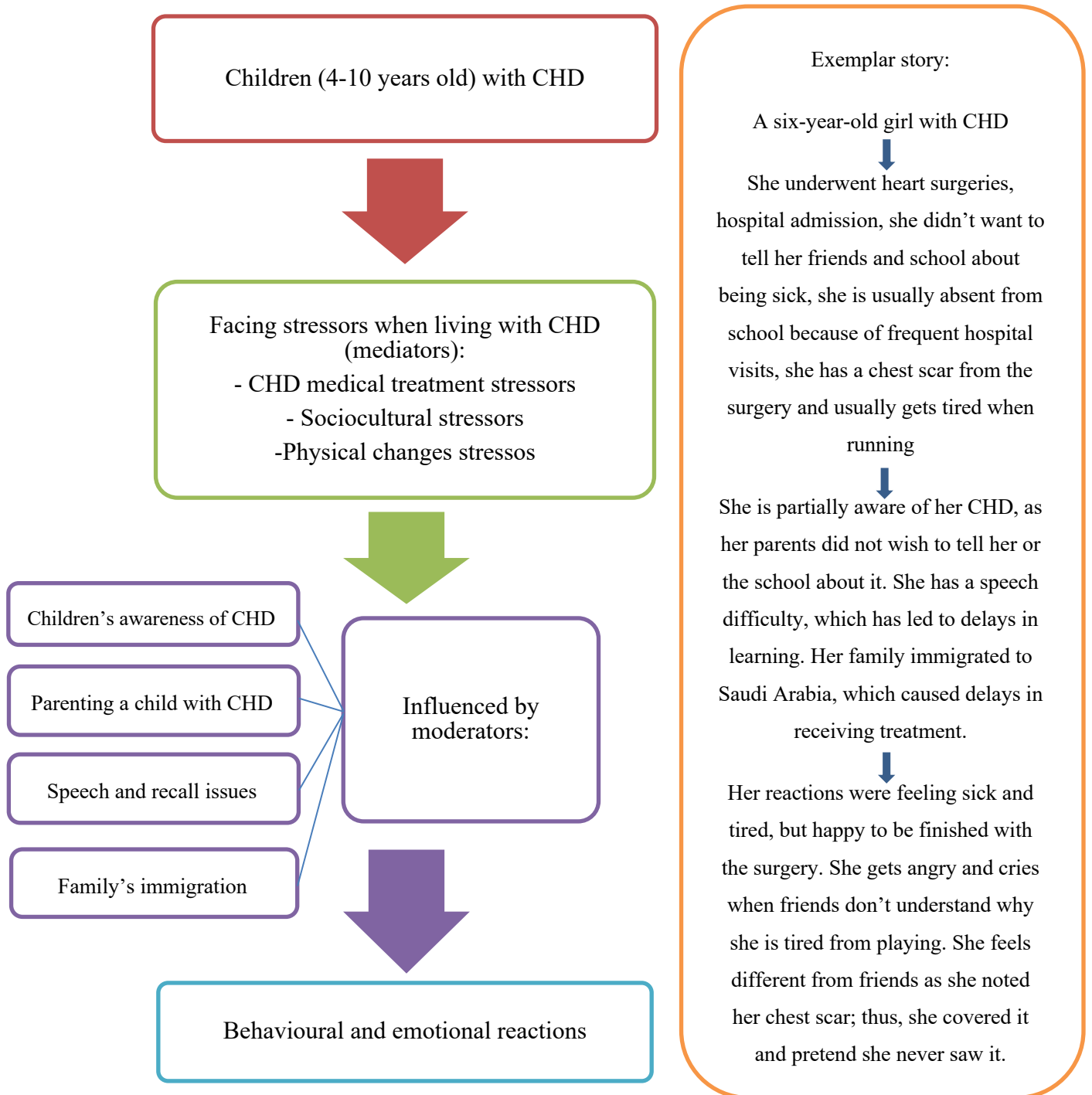
11.5 Integration of the emergent theory with existing theories

Since this substantive theory was generated based on Charmaz's approach of GT, this theory was generated in the context of SA and did not seek generalisability within a larger context. Charmaz's GT aids deep and rich understandings of a phenomenon in a local context, and generalising the generated theory to another or wider context is not a priority (Singh and Estefan, 2018). However, the researcher recommends testing this substantive theory within different contexts and populations for future research work to expand its implication among a larger group of children with CHD and/ or children with other long term conditions.

This section discusses the integration of the current substantive theory with existing theories. To reach a higher level of theoretical abstraction, integrating

the emerged theory to the existing theories within the researched area is vital to compare, contrast, or identify expansions to existing theories (Urquhart, 2012). For the theory integration with others, an overview of the current theory is revisited as follows. The emergent theory of this study proposes that children with CHD in SA experience behavioural and emotional reactions due to facing CHD medical treatments' stressors, sociocultural stressors, and physical changes' stressors. Furthermore, it is suggested that the children's behavioural and emotional reactions towards the stressors are influenced by their awareness of their conditions, parenting, speech and recall issues or delays, and family immigration. The flow chart (figure 11.1) demonstrates the theoretical relationships of the current theory.

Figure 11. 1: Flow chart of the emergent theory

Children (4-10 years old) with CHD	Exemplar story:
↓	A six-year-old girl with CHD
Facing stressors when living with CHD (mediators): - CHD medical treatment stressors - Sociocultural stressors -Physical changes stressos	She underwent heart surgeries, hospital admission, she didn't want to tell her friends and school about being sick, she is usually absent from school because of frequent hospital visits, she has a chest scar from the surgery and usually gets tired when running
Children's awareness of CHD Parenting a child with CHD Speech and recall issues Family's immigration → **Influenced by moderators:**	She is partially aware of her CHD, as her parents did not wish to tell her or the school about it. She has a speech difficulty, which has led to delays in learning. Her family immigrated to Saudi Arabia, which caused delays in receiving treatment.
↓	Her reactions were feeling sick and tired, but happy to be finished with the surgery. She gets angry and cries when friends don't understand why she is tired from playing. She feels different from friends as she noted her chest scar; thus, she covered it and pretend she never saw it.
Behavioural and emotional reactions	

This section briefly discusses several theories that have a relationship to the current emergent theory. These theories are based on similar concepts to the current theory, which involve emotions, behaviour, stress and stressors, child development, biopsychosocial needs, and family relationships. Several similarities and differences and highlights of what the current theory adds or how it differs from the other theories are also provided. Finally, a summary of the integration and comparison of the current substantive theory with the existing theories is provided in Table 11.1.

11.5.1 Biopsychosocial model

Engel (1977) transformed the patient care, physician-patient relationship, and holistic understanding of the patient's needs through the Biopsychosocial (BPS) model. In his BPS model, Engel included the need to understand the social context of where the patients experienced illness and the contribution of psychological disorders to the illness (Engel, 1977). He critiqued the biomedical model and developed a more holistic and extended model that considers the individual's psychological and social needs, besides the biological needs (Borrell-Carrió et al., 2004). The BPS model argues that the experiences of people are more complex than a linear relationship between just two factors; indeed, in his BPS model, he provided an insight into how a combination of factors in biology, psychology, and sociology would influence human experience at different levels and intensity (Astakhova and Hogue, 2014).

The contribution of the BPS model has been identified not only in medical practice but also recent medical education and research (Adler, 2009) and in studying human behaviour such as heavy work investment and workaholism (Astakhova and Hogue, 2014). Researchers have also used the BPS model in studying childcare and family-child care and relationships (Atkins et al., 2012; Cataldo et al., 2019). For example, Atkins et al. (2012) studied children who had recovered from a paediatric intensive care unit. They demonstrated an

example of the flexibility of using BPS within a variety of fields and research methodologies. In the study, children's findings were integrated with the three concepts of the BPS model (biological, psychological, and social) using GT methodology (Atkins et al., 2012).

Recently, researchers have also added the spiritual domain to the other three domains of BPS called BPS- spiritual model, which is believed to contribute a more holistic view of the patient's care (Katerndahl, 2008; Saad et al., 2017; Sulmasy, 2002). In order to test the applicability of integrating the spiritual domain in healthcare, Saad et al. (2017) recognised that health care providers must understand the different dimensions or meanings of a person's spirituality. Spirituality can range from religious faith or other non-religious aspects; an example of spirituality is "spiritual-religious coping" where emotional support practices are adopted to reduce distress from illness (Saad et al., 2017).

The BPS was selected for the integration with the current theory because it discusses more than one similar aspect in the current theory. All three domains of BPS, biological, psychological, and social, are also discussed in the current theory; thus, BPS is related and comparable with the current theory. Moreover, as discussed above, previous studies have shown that BPS was used to explore children's experiences by describing complex relationships between the three domains of BPS. Likewise, the current theory suggests complex interrelationships between the children's CHD and their behaviour and emotions as they face stressors. These stressors in current theory include the domains of BPS biological, psychological, social, and other aspects and influencing factors. The BPS's biological domain resembles the stressor of CHD medical treatments. There is a link between the biology of CHD and genetics and the child's behavioural and emotional reactions (see section 11.4.1). The psychological domain of BPS was addressed in the current theory in the context of child's emotions and behaviour and their reactions towards

facing stressors. Moreover, the social domain of BPS was explored in current theory in the sociocultural stressors of children with CHD.

However, different relationships between the domains were proposed in the current theory, as BPS describes that biological, psychological, and social factors influence individuals' experiences (Astakhova and Hogue, 2014). Therefore, this theory proposes different relationships, that the psychological (behaviour and emotions) are reactions resulting from facing stressors that include biological and social domains. Furthermore, the current theory added the cultural aspect of where the children live which acts as one of the mediators between the relationships of children with CHD and their behavioural and emotional reactions. Another addition is that four influencing factors can influence and moderate the relationships in theory. Therefore, the addition of cultural aspects and influencing factors can provide a holistic view of children's experiences and be validated for implications in different cultures and contexts. Table 11.1 provides a summary of the similarities and differences between the BPS model and the current theory.

11.5.2 Behaviourism

Behaviourism, as launched by Watson (1913), is a theory of learning, and it describes how human behaviour is influenced by environmental factors in a stimulus-response action, through what Skinner (1938) called "operant conditioning". The "operant conditioning" explains how an individual can learn from the consequences of any behavioural changes by rewarding or punishing the behaviour (Skinner, 1938). Skinner described human behaviour as a cause of action; for example, if reinforcements followed the behaviour, it would probably be recurrent, while unreinforced behaviour would be diminished. He identified a contribution of operant conditioning in shaping human behaviour by using the punishment and rewarding principles to aid in adapting particular behaviour or refraining from another, which can be adopted in school education and for learning purposes (McLeod, 2018).

Further to the "operant conditioning" theory, Edward Thorndike proposed the principle of "law of effect", in which he explained that behaviour would be repeated if followed by desirable consequences. In contrast, undesirable consequences leads to less recurrence of the behaviour (Cherry, 2019).

Watson's theory of behaviourism and operant conditioning by Skinner were comparable to the current theory since they share the same concept that behaviour responds to stimuli. The current theory suggests that the behaviour exhibited in children with CHD were their reactions (response) to several stressors. In addition, behaviourism can aid the understanding of children's behaviour and dealing with children's behaviour, which is found to be related to the current theory's understanding of the behaviour of children with CHD. The current theory adds to behaviourism that even though children's behaviour is a response to a stimulus, other factors can influence how the children respond to those stimuli. For example, in this study, a boy tends to hide his chest scar and not share his condition with others. This behaviour was a reaction of the child experiencing the stress of having to deal with a chest scar from heart surgery, which, according to behaviourism, is considered a stimulus and led him to respond and cover it. However, the current theory adds that his behaviour of covering the scar was also influenced by parents instructing him not to disclose the condition to others and not show them the scar. A summary of the similarities and differences between behaviourism and the current theory is provided in table 11.1.

11.5.3 Theories of emotions

The James-Lange theory of emotions suggested that emotions happen as a reaction to physiological changes with environmental stimuli. Thus, an individual would have a physical response to environmental stimuli, then experience emotional reactions according to how the stimuli were interpreted (James, 1948). For example, if you saw a wild animal approaching and your heart started racing, according to the James-Lange theory, you would interpret

this physical reaction as experiencing a dangerous event, and, therefore, feel frightened. Hence, the James-Lange theory suggested that emotions are a consequence of physical responses. On the other hand, the Cannon-Brad theory of emotion challenged and argued that emotional reactions could occur independently or concurrently with physical responses (Cherry, 2020; Sullivan, 2009). The Cannon-Brad theory suggested that emotions arise as a response to a brain stimulus to a message sent by the thalamus, and then a physiological reaction occurs (Sullivan, 2009). James-Lange and Cannon-Brad were selected to integrate the current theory because both theories describe how an individual's emotions could happen. Therefore, they are suitable to explain children's emotions. An example of relying on theories of emotions, the James-Lange and Cannon-Brad theories, in understanding children's emotions, was provided by Gupta and Wani (2020). In their review through the illustration of emotions' theories, they described how children could learn emotions as they grow and learn how to deal with their emotions.

Compared to the current theory, both James-Lange theory and Cannon-Brad theory suggested that emotions are reactions to events or stimuli, which is in line with what this theory suggests. The current theory is grounded on children experiencing emotional reactions to stressful events related to CHD. As James-Lange theory and Cannon-Brad theory differ in the presence or sequence of the physiological changes to the emotional reactions, children in this study also revealed emotional reactions in response to physiological changes of having CHD. Children experience stressors related to having CHD (physiological change); thus, they show emotional reactions. However, children's emotional reactions to CHD related stressors (physiological changes) were proposed to be influenced by several factors, which the current theory can add to the existing emotional theories. For example, a boy cannot run and play for a long time and compete with friends because of the CHD (physiological change); thus, he felt sad and frustrated (emotional reaction)

because he was not aware of his condition and did not understand how to deal with getting tired (influencing factor).

11.5.4 Family systems theory

Family systems theory (FST) by Bowen (1978), offers an understanding of the family's interaction and describes the family as a unit or system of emotional connections between the family members. This system has deep and complex relations between the members; each member has a function in the family and they can influence each other (Hammond et al., 2015). According to Bowen, the critical features of the family system are boundaries (which defines who are the family members), equilibrium (when the family members attempt to restore a comfortable form in case of crises), and bidirectional (one member impacts another and therefore impacts the whole system) (Lang, 2020). The family system theory can be used in assessing a family's adaptation, for example, in moving to a new country (e.g. immigration), in which the structure and processes of the family can be assessed to support the family to cope and adjust to the new environment (Lang, 2020).

The FST has been implemented in children and adolescents clinical practice and understanding family's contribution to medical treatment. It identified the values of child-parents interactions or bonding. It emphasised the concept that family disturbance (e.g. divorce) can impact child-parent relationships (Webster-Stratton and Hooven, 1998), or a child's illness can disturb the family system (Dadds et al., 1988). Gilbertson and Graves (2018) demonstrated that through the perspective of FST, the family dynamic and role of parents as caregivers were found to have contributed to the healthier heart status of a child with a heart condition. Positive parenting skills and adopting a positive, healthy lifestyle relate to improvement in their children's heart health through playing role models to their children and encouraging the family members to eat healthily, engage in activities, and avoid habits harmful to health (Gilbertson and Graves, 2018). Involvement of family in the care and

management of health condition collaboratively with healthcare providers is identified as a family system approach (FSA) (Reeves et al., 2013), or family systems nursing (FSN), where there is a perspective for practice that promotes involvement of the family unit in the healthcare of a family member who has illness instead of focusing on managing the health of individuals (Duhamel, 2017). In addition to moving theory into the implementation of clinical practice, Duhamel (2017), in her study, aimed to optimise family care, particularly family nursing practice and provided insights to using theoretical knowledge in clinical practice.

A comparison of the current theory with the FST revealed similarities. The current theory agrees with the FST in the concept of one family member impacting another; for example, parents' beliefs and parenting skills influenced children's awareness of CHD. Also, as discussed previously, parents implementing supportive, positive parenting skills can promote the way the children reacted to stressors; therefore there are less behavioural and emotional issues, which is similar to the perspective of a family system theory of parents influencing their children with chronic illness. Thus, FST supports one crucial aspect of the current theory, which suggests that parents can influence their children with CHD. Moreover, deep family relationships and connections were also demonstrated in the current study, which was observed in child-siblings and child-parents relationships. The current theory further builds on FSA by broadening the scope of its implementation for children with CHD within the Arab culture in SA. This theory suggests that cultural beliefs of family and healthcare providers impact the care delivery for children with CHD. Thus, FSA implementation and introduction of family involvement in the care of children with a chronic condition should be sensitive to cultural diversity.

Moreover, immigrant families of children with CHD would benefit from the implementation of FSA and future research of FSA in immigrant families of

children with CHD. As described above, FSA allows health care providers and other professionals to assess the family structure and needs when immigrating to a new country, one of this study's main recommendations. Table 11.1 summarises the similarities and differences between FST and the current theory.

11.5.5 Theories of stress and stressors

There is an identified relationship between the physiological changes and stress as recognised in the stress-response theory by Selye (1956). He identified stress as a response and defence mechanism, leading to diseases or death (Cummings and Sanders, 2019). In his theory, Selye (1956) described the symptoms of response to stress as General Adaptation Syndrome (GAS). Three stages of adaptation occur namely alarm reaction, resistance stage, and exhaustion stage. Commonly, the physical, emotional, and mental status gets negatively impacted in the exhaustion stage if the child cannot adapt to the stress within the first two stages (Selye, 1956).

Another explanation of stress adaption was identified by a nurse theorist Roy in 1964 (Roy and Andrews, 1991), as Roy's adaptation model (RAM) in which she drew upon the stress theories by Selye and other theories (Rice, 2011). Through RAM, Roy described three stimuli of adaptations: focal stimuli in which there is a need to face a demand (e.g. need for surgery), contextual stimuli, which is about the factors accompanied by the existing demand (e.g. fear of surgery or dying), and residual stimuli, that are affecting the emotions and behaviour of a patient or the surrounding people. Later, the transactional theory of stress and coping (TTSC) was developed by Richard Lazarus (1966). It was acknowledged that external factors such as personal or social could impact the intensity of the stress faced by individuals. Lazarus also integrated stress and the ability to cope with it, and that the way a person appraises or views the stress determines how the person can cope with it (Cummings and Sanders, 2019; Lazarus, 1966).

Relying on the above stress theories, it can be implied that children learn different ways of responding to the stressors to adapt to life events' stressors. Children's life changes, such as illness, can cause stress in their lives. Their ability to adjust or deal with stressors is crucial to prevent psychological issues (e.g. emotional and behavioural problems) and physiological issues (Selye, 1956). This is found to be related to the current theory, where similar relationships were identified between CHD and children facing stressors associated with living with CHD, thus exhibiting behavioural and emotional reactions. Moreover, similar to Lazarus's theory, the current theory suggests that influencing factors are vital in children's reactions to stressors. Therefore, theories of stress were comparable to the current theory; a reaction to stressors is considered the main concept in the core category of the current theory.

The current theory revealed several similarities with these theories, mainly that psychological changes (behaviour and emotions) happen in response to stress. However, the current theory provides a concept of understanding chronic illness-related stress in children, where disease circumstances alongside other life events (e.g. immigration), as influencing factors, can impact the stress or the way the child with CHD reacts to stress. For example, in this study, a child confronted with the stress of undergoing surgery was also influenced by being an immigrant child, which added to the stress level; thus, they exhibited anger and crying episodes as reactions to stress. In addition, the influence factor of immigration played an important role in the child's exposure to the stress of surgery as adapting to a new environment with immigration. So, the current theory builds on the stress theories with a unique view of a child's reactions to disease-related stress while living with CHD, considering several influencing factors. Table 11.1 summarises the similarities and differences between stress theories and the current theory.

Table 11. 1: Summarised comparisons of current substantive theory with existing theories

Current Theory Existing theories	Similarities to the current theory	The current theory adds/ differs
BPS model	• The domains biological (CHD treatment), psychological (behaviour and emotions), and social domains are mutually explaining the children's experiences • The relationship between the domains are complex and contribute to children's health care at different levels	Domains in current theory are suggested as: • Biological and social domain of BPS: as CHD treatment and sociocultural stressors in current theory. • Psychological domain of BPS (behaviour and emotions): as children's (outcome) reactions to stressors This theory adds: Some factors influence the relationship between the stressors and behavioural and emotional reactions.
Behaviourism: The operant conditioning	Behavioural reactions are response from external stimulus.	This theory adds: The relationship between behavioural reactions and the external stimulus (which in this theory are stressors), can be moderated by influencing factors.
Theories of emotions	Emotions occur as reactions to physiological stimuli. In this study the physiological stimuli are the CHD and related stressors.	This theory adds: Emotional reactions to stressors (stimuli) are moderated by influencing factors.
Family system theory	Family is connected with deep relations and one member can impact another. Parents as caregiver have an influence on the health of their children.	This theory adds: • Additional variables in family's relationships • A different cultural context (Arab). • Immigrant families of children with CHD.

Theories of stressors	Behaviour and emotions occur as a result of a response to stress	This theory adds: • Understanding for CHD-related stress in children. • Children's reactions to stressors influenced by factors.

11.6 Recommendations for future research

This study provides several recommendations for future research concerning researching children with CHD in SA, which are summarised from the discussion above:

- It is recommended to test the substantive theory further in the population of SA and in different cultural backgrounds on children with CHD and other chronic illnesses.

- More qualitative research is needed to explore views about the behaviour and emotions, not only for the children's and young people's views, but also the proxy reports of their families.

- Further research should be conducted in Saudi Arabia and other Arab countries on children with CHD and their families.

- Explore doctors' and nurses' views in Saudi Arabia about the behaviour and emotions of children with CHD.

- Research children's and family's needs for support regarding the behaviour and emotions of children with CHD.

- Explore the frequent invasive procedure and its relation to children's behavioural and emotional reactions with CHD qualitatively.

- Investigate the transitional period from pre- to post-surgery and its relation to the behaviour and emotions of children with CHD.

- There is a need for exploration of child-parent relationships or attachment in children with CHD.

- Siblings jealousy and its impact on developing stress and behavioural and emotional issues in children with CHD.

- Future research is required for assessing the link between school and friendship the development of social stress and behavioural and emotional reactions.

- Physical activity restrictions in children with CHD and its impact on children's friendship and social skills. Identify the development of any behavioural and emotional issues.

- Investigate children's, families', and health care providers' readiness to enhance the awareness of young children with CHD about their condition and their treatments plans.

- Further explore the parent's parenting styles of children with CHD and its relationship to the development of children's behavioural and emotional issues.

- Research children with CHD with immigrant families in SA about their experiences in seeking medical care for their children, school admissions, and any learning difficulties (speech and recall issues).

- Investigate any disparity in the relationship between immigration and children with CHD among immigrants from different cultural backgrounds in other countries.

11.7 Implications for future practice

This study highlights the need for developing interventional programs that aim to reduce children's behavioural and emotional issues because of CHD related stressors, and enhance the awareness of healthcare providers, children and families, schools and social services in SA. Special considerations could be provided for immigrant children with CHD and their families, to help them overcome barriers in accessing healthcare and social services (e.g. schools). Preoperative preparation for the children and families is suggested to be vital in reducing stress and anxiety. The transitional period from pre-surgery to post-surgery was described by children with CHD, in previous studies, as a tense and emotional time as demonstrated in a review by Svensson et al.

(2020), and transition from hospitalisation to daily life activities after surgeries was found to be stressful for children with CHD and their families (Kendall et al., 2003). In Kendall et al. (2003), parents were introduced to a suggested program that aimed to provide support for children aged 5-18 years old with CHD in the UK, and the parents' views were gathered regarding a suitable plan for their children. The suggested program included parts for educating children and enhancing their knowledge about their condition and treatments, another part for exercising to enhance the children's physical strength, and a final part involving supporting children to socialise with friends and avoid any related stress or issues (Kendall et al., 2003). Moreover, a study conducted in Ireland by Kennedy and Howlin (2021), demonstrated how parents prepared and educated their children about their conditions and the upcoming surgery using a booklet from the hospital which helped the children to understand the pre-operative period through stories. Children's pre-operative anxiety levels were improved and children were excited to meet the character in the booklet story at the hospital. Parents, however, found it difficult to find resources to educate themselves about the children's conditions and to discuss sensitive topics with children; indeed, they appreciated when doctors and nurses talked directly to their children about the procedures (Kennedy and Howlin, 2021). These findings are encouraging to identify the positive outcome of children's pre-operative periods when involving parents in preparing the children with CHD for hospitalisation and surgeries in SA.

A similar interventional program can be adopted for application in SA, after assessing parents' and children's needs regarding types of support needed. Previous studies in SA have also demonstrated that alleviating children's anxiety could be achieved through conducting physical, and psychological assessments and support prior to surgery (Nandi, 2013; Noman and Bawazir, 2016). However, these studies did not address the type of psychosocial support that these children and their families in SA might need, and if the children's want to be informed about their conditions and procedures in SA. Moreover,

on the Saudi Ministry website for public awareness, there is no information that helps to prepare the child or family for a child's hospitalisation (Saudi-National-Portal-for-Government-Services-[GOV.SA], 2021). Therefore, this evidence supported the need for assessing children's and family's needs for psychosocial support, and then to develop an interventional program to provide the required support in SA. Through this program, doctors, nurses, and policy makers can advocate for children with CHD and take the initiative to prepare children pre-operatively, explain the surgery to them, and encourage them to ask questions using child-friendly approaches (e.g. art-based approach). Preoperative education for children and families, as recommended by the Royal College of Nursing (RCN) (2020), should be provided as soon as surgery is planned using a child friendly environment and simple language. Nurses have a role of providing information to children, which can be orally or through leaflets or links to useful age-appropriate websites/digital apps and ensure that children and parents are provided with sufficient psychosocial support (RCN, 2020).

The proposed interventional program can also include developing an assessment tool for assessing the behaviour and emotions of children with CHD. Moreover, school personal and social care workers could provide specialised support for children with CHD in SA. This support will assist children who experience periods of absenteeism because of their sickness to re-engage in school work, physical activities with peers and minimise stress related to learning and friendship. The schools in SA usually employ a school nurse, who has a role in providing support and primary health assessment and care for children. Through the introduction of this proposed interventional program, the school nurse can play a vital role in assessing children with CHD, their needs for support, and refer them to professionals as needed. This intervention program can also include educating children at schools, their peers, and other school personal about the children's condition and the related stressors. Therefore, children's awareness of their conditions and the bodily

changes due to disease will be enhanced; thus, children learn to adapt positively and avoid the likely adverse behavioural and emotional reactions to the CHD related stressors. Accordingly, actions could be taken through the suggested interventional program for supporting the children dealing with their physical changes. The parents have a significant role in observing their children's day to day skills, issues with speech and recall, and behaviour and emotions to refer them to the healthcare providers. The programs can also include educational services for the parents to learn positive parenting styles and the contribution of enhancing their children's awareness to their behavioural and emotional wellbeing.

Challenges of applying this interventional program in SA could be regarding cultural beliefs of discussing such sensitive topics with children, especially for parents who want to protect their young children's feelings from knowing about their condition. Moreover, the readiness of doctors and nurses to collaborate in developing such programs needs to be assessed, as well as getting parents' and children's views on types of support they need. Another possible challenge for implementing such programs in SA would be regarding attaining approvals from the Ministry of Education and Ministry of Health, which require going through lengthy administrative procedures. Yet, such challenges can be minimised with increasing the awareness of families, and healthcare providers about the potential benefits of implementing such interventional programs for children who are dealing with their condition and related stress and behavioural and emotional issues.

11.7.1 Nursing implications

In addition to the implications provided above for healthcare providers, nurses play an essential role in enhancing families' and public awareness about CHD. Nurses can lead the role of educating parents and their children about CHD. Also, establishing a trust relationship with children and parents can motivate the families to approach the nurses with any question about CHD and raise

any issues. The implication for nurses for families of children with CHD is as follows:

- Check, with the parents, the children's readiness to comprehend any related information, and assess their level of understanding and start with the education of body parts and CHD.

- Support the parents on disclosing disease-related information to their children and explaining the undergoing medical procedures, including benefits and side effects.

- Educate the children on dealing with any physical symptoms or changes (e.g. activity limitation and chest scars).

- Work collaboratively with other health care providers in providing psychosocial support groups for children with CHD and their families.

- Assess the needs of immigrant families, assess the presence of any stress or trauma and provide adequate support or referral to psychosocial support.

11.8 Strengths and limitations

11.8.1 Research design

GT methodology provides clear and explicit guidelines, which direct a novice researcher on how to start and finish their projects, which aided the researcher in conducting this study (Charmaz, 2006). Another strength of conducting GT is the richness and depth of data because GT methodology encourages the researcher to leave the surface and go deeper into participants' experiences and lives (Charmaz, 2006). Moreover, the constructivist approach of Charmaz enabled the researcher to bring and integrate personal experiences as a child health nurse into the data analysis (Charmaz, 2014). It is a methodology of inquiry where there is scope for exploring, understanding and describing a phenomenon and generating a theory (Glaser, 1978). However, a limitation of GT methodology is that it can be exhausting and challenging for a novice

researcher to conduct, and the theory development phase can consume time to scale it up to a fine theory (Annells, 1997; El Hussein et al., 2014). The researcher in this study faced the challenge of learning to conduct a qualitative study for the first time and elevate the data analysis level up to generate a substantive theory within a limited timeframe.

11.8.2 The sample

This study has a limitation in including a relatively small sample (n=20, 10 children and 10 parents). Including a small number of participants was due to the time limitation to continue approaching more eligible families who had difficulties participating at the time of the data collection. However, it is believed that this number of participants did not reduce the value of this study and the new contribution of knowledge, as this study provided primary knowledge that was grounded from participants' views about children with CHD for the first time in SA. Also, the researcher intended initially to recruit an equal number of male and female children with CHD. However, most eligibility according to the study criteria was identified among male children with CHD.

Theoretical sampling is a vital phase in GT; its aim is to expand the scope and generalizability of the generated theory within larger and various substantive groups, and to move the theory from substantive to formal theory (Urquhart, 2012). However, this was not feasible in the current study due to time limitations. More time would have allowed for the recruitment of more female children and fathers of children with CHD, as indicated in the theoretical sampling frame. Furthermore, as identified earlier, because the researcher followed Charmaz's approach of GT, generalisability of the emergent theory was not a priority. The focus was rather exploring a deep understanding of children's behaviour and emotions through perceptions of children and parents, which was achieved by generating this substantive theory.

The longer time required for the proper application of theoretical sampling was acknowledged by Timonen et al. (2018) as a challenge for researchers to keep in mind and plan for it. Furthermore, including additional data collection methods or recruiting specific participants in theoretical sampling may require additional ethical considerations, which can sometimes be hard to achieve within a restricted time frame (Timonen et al., 2018). The time restriction was also a challenge faced in participants' recruitment as recruiting from more than one hospital in Jeddah would require more time. However, the approached hospital is a large general hospital in Jeddah that provides care for a large population in Jeddah, including nearby cities and suburban districts. Thus, recruiting participants from such a setting is believed to be a reason for including participants from different Arab countries. Finally, due to many immigrant families seeking medical care at this hospital in Jeddah, this has provided an opportunity to include immigrant families and study this influence on children with CHD.

11.8.3 Data collection method

Collecting data through individual face-to-face interviews was challenging for children as they can easily be distracted. However, in face-to-face interviews with an art-based approach, they were quickly engaged in the talk. Face-to-face interviews allowed direct interactions between the researcher and the participants and made the participants feel more comfortable. Moreover, face-to-face interviews were also helpful and convenient for parents because they were already present with their children at the hospital; thus, they found it suitable to be interviewed straight after their appointments. However, some parents preferred to be interviewed via the telephone due to their time restrictions. Although, telephone interviews can result in gaining less information from participants, they can be a pragmatic option and cost-effective for the participants (Rahman, 2015). Indeed, in this study, telephone interviews were found to be more convenient for some families and the

researcher, especially as the researcher experienced several occasions when the parents were repeatedly interrupted by their children during the face-to-face interviews. In contrast, during the telephone interviews, parents found it easy to keep their children busy playing in one room or they even went to a quiet place to be interviewed (for example, talking in the car). Thus, in this study, it was found that telephone interviews could eliminate some distractions during the interviews.

There were some occasions where the interview was recorded by mobile phone instead of a digital recorder. Ethical approval was obtained to use a mobile that was specified for research purposes only. In several interviews, the researcher found that participants were more relaxed and able to freely express their views without the presence of a digital recorder and when they were recorded using the mobile, as they were more familiar with the mobile than a digital recorder.

Most of the recruited child participants were in the following-up phase of their CHD, where they had undergone surgical procedures and catheterisations when they were younger. This could suggest a criticism of obtaining retrospective accounts from children and parents, which included recalling events related to the children's emotions and behaviour when the procedures were done in the past. However, children did not seem to have difficulty to recall related events, especially with the use of pictures and drawings. Parents were also able to recall and report their children's behaviour and emotions without showing signs of difficulty remembering related events. Thus, combining the reports from parents and children provided a more holistic understanding and was considered as a strength in this study. Moreover, it is believed that the children who were unaware of their conditions could not provide accurate emotions and behaviour toward the CHD. Nevertheless, valuable insights were obtained from their parents' proxy reports. Furthermore, some children were less aware or unaware of their conditions,

which brought an essential insight into the scaling up the theory and finding links between the categories.

Using the art-based approach in children's interviews

Gathering accounts of 4-10 years old through interviews was challenging in order to draw their attention to the interviews; thus, employing an art-based approach in children's interviews was important. During the interviews, some children tended to engage deeply, while drawing, and did not talk. In these cases, the researcher reminded and explained again to the children that drawing would be concurrent with talking and that the child should stop drawing for a while and talk. Children followed these instructions and were able to use the pictures and drawings in their talking. Indeed, valuable perceptions from children were attained using pictures of emojis and drawings.

A challenge was raised when some parents, who preferred to attend their children's interviews, tried to talk to their children to encourage them to speak if their children did not respond to the question promptly. However, the researcher reminded the parents that children should be given sufficient time to respond to questions at their own pace without the influence of their parents. Consequently, parents were very cooperative with the researcher's wishes. One limitation about parents' presence during children's interviews is that it might have influenced the children's response. Children might feel hesitant or uncomfortable to talk freely in the presence of their parents, for example, talking about feelings towards family interactions, even though their parents' presence can also be comforting for both children and parents (Spratling et al., 2012). However, successful children's interviews were conducted with proper instructions to parents and children, and rich information was gathered from children with and without the parents' presence. Additional challenges of using an art-based approach were provided in the methods chapter (Chapter 4).

11.8.4 Data analysis

As a novice researcher who is conducting GT and analysing qualitative data for the first time, it was challenging for the researcher. However, following Charmaz's approach of GT and the clear guidelines of GT for analysis have facilitated the analysis stage and enabled the researcher's personal experience to be integrated with the interpretations.

The researcher gave pseudonyms for the children and parents in this study to ensure participants' confidentiality. However, there is a debate around whether the researcher should choose the pseudonyms or whether it should be a decision whereby the researcher asks the participants to choose, to enhance participants' engagement in research. Participants can select names that have social or psychological meanings, such as the name of a memorable person (Spratling et al., 2012). Even though the researcher made the pseudonym selection in this study, they were chosen to be entirely different from the participants' actual names. Furthermore, they were selected bearing in mind the culture and ethnicity of participants (e.g. they were common names in Arab countries).

Another limitation of this study is that the researcher's interviews were translated from Arabic to English for analysis purposes. The impact of translated interviews from one language to another on maintaining the accuracy of findings was demonstrated by Al-Amer et al. (2015). Because there might be several possible meanings for one script and the lack of standardised procedures for translating qualitative interviews, the researcher faces the challenge of finding the most accurate meaning for the script when translating to another language (Al-Amer et al., 2015). Moreover, the researcher is not a specialist in translation, and it was not possible to approach a professional translator because of confidentiality and ethical issues. Yet, the researcher is a native Arabic speaker who can understand different cultural and social expressions and find their meanings in the English language.

Moreover, with anonymity and confidentiality protected, the researcher selected part of the script and asked a colleague who is fluent in both Arabic and English languages to cross-check the translation.

11.8.5 Theory generation

It is acknowledged that the substantive theory of children's behavioural and emotional reactions towards stressors related to living with CHD, with the presence of influencing factors, has some limitations concerning the process of generating a theory. GT methodology was followed to generate a theory, but no theory testing was done due to time limitations. Because conducting a GT aims to generate a theory (Charmaz, 2006; Glaser, 1992) and is not testing the theory, this study did not test the emerged theory among children with CHD in SA. Moreover, testing this substantive theory in another setting, cultural background, and children with other chronic illnesses was identified as one recommendation for future research. However, theory integration to related literature and existing theories can improve the analytical generalisability of the theory, which was applied in the current study (Urquhart, 2012).

For a novice researcher conducting a GT study, it was challenging at first to confirm the emergence of a well-developed substantive theory. However, it was ensured that each step of generating a substantive theory was followed as guided by Charmaz, with proper engagement in memoing and diagramming from an early stage of data collection and analysis. Also, the cross-checking of coding stages, analysis and theory conceptualising with the supervisors has provided adequate support and guidance. Moreover, attending troubleshooting seminars for GT application have assisted in gaining confidence and certainty in generating the theory.

11.9 Concluding remarks

This thesis presents the first study providing an in-depth understanding of the behaviour and emotions of children 4- 10 years old with CHD in SA through exploring their voices and their parents' proxy reports. This study introduced a substantive theory that proposes *children's behavioural and emotional reactions towards stressors related to living with CHD with the presence of influencing factors.* The theory highlights that children's behavioural and emotional reactions are mediated by stressors related to having CHD and moderated by influencing factors. All children in this study were equally facing stressors of CHD medical treatments, sociocultural, and physical changes. It was found that parenting and child's awareness of CHD were broadly influencing children's behavioural and emotional reactions to stressors. Speech and recall issues/ delays, and family immigration are other identified factors that influenced the reactions to stressors of some of the children with CHD in this study. Through integrating the emergent theory with other existing theories in the literature, this substantive theory adds extended meanings or concepts to what was already known about children's behaviour and emotions as explained by other theories.

The findings of this thesis have identified several recommendations for future research, taking preventative measures, and future clinical implications for healthcare providers. This study will help nurses, other healthcare providers, and families to better understand the behaviour and emotions of children with CHD, improve care delivery for children with CHD in SA, and reduce the impact of CHD on the behavioural and emotional changes in children.

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Appendices

Appendix-I: Literature review search strategy:

Database: (Ovid) Medline and Psych Info, including updated search in 2021:

Search in years 2000 and 2017	Updated search between 2018 and 2021
1 exp Heart Defects, Congenital/ (74924)	160453
2 exp Heart Diseases/cn [Congenital] (3482)	6764
3 (congenital$ adj3 heart).tw. (19987)	43275
4 (congenital$ adj3 cardiac).tw. (3035)	5976
5 heart defect$.tw. (6147)	12660
6 guch.tw. (67)	94
7 ACHD.tw. (236)	696
8 or/1-7 [congenital heart disease] (83616)	182560
9 exp Child/ (945895)	2023902
10 exp Adolescent/ (1106247)	2136540
11 exp Infant/ (531944)	1194743
12 ("school age child*" or "0-11 year*" or toddler*).tw. (10542)	33370
13 ("young adult*" or "young person" or "young people" or p?diatric* or teen*).tw. (241347)	599609
14 Pediatrics/ (29509)	82173
15 or/9-14 [children] (1877174)	4067540
16 ((psychosocial or psycho-social) adj3 (status or adjustment or condition or problem* or issue* or disorder*)).tw. (7177)	19516
17 exp Behavior/ (1028988)	3157741
18 exp Emotions/ (143639)	534943
19 (behavio?r$ adj3 (issue* or problem* or disorder* adjustment)).tw. (17572)	68257
20 exp Conduct Disorder/ (2723)	6754
21 (aggression* or emotion* or behavio?r).tw. (518690)	1748870
22 16 or 17 or 18 or 19 or 20 or 21 (1396738)	4373826
23 exp Child Behavior/ (14284)	26252
24 exp Infant Behavior/ (2890)	3691
25 exp Adolescent Behavior/ (23602)	36470
26 (Behavio?r adj3 (child$ or infant* or adolescent*)).tw. (15888)	60371
27 exp Child Behavior Disorders/ (9635)	20658
28 23 or 24 or 25 or 26 or 27 (52659)	125396
29 8 and 15 and 22 (1404)	2696
30 8 and 28 (209)	363
31 29 or 30 (1422)	2753

Database: (EBSCO) CINAHL, including updated search in 2021:

	Search between 2000 — 2017		Updated search
S34	S9 AND S32	38	68
S33	S9 AND S16 AND S24	472	293
S32	S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31	18,064	43092
S31	"child* behavio#r disorder*"	4,184	9429
S30	"child* w3 behavio#r w3 disorder*"	1	4
S29	"infant* behavio#r"	1,963	3739
S28	"infant* N3 behavio#r"	1	3
S27	"adolescen* behavio#r"	5,610	15812
S26	"child behavio#r*"	11,055	25666
S25	"child N3 behavio#r*"	1	5
S24	S17 OR S19 OR S20 OR S21 OR S22 OR S23	395,746	2204063
S23	S20 w3 S18	8,513	21384
S22	"conduct disorder*"	727	1876
S21	emotion*	47,844	121061
S20	behavio#r	150,677	395886
S19	S17 w3 S18	4,007	9414
S18	status OR condition OR problem* OR issue* OR disorder* OR adjustment	737,586	1693670
S17	"psychosocial" OR "Psycho-social"	258,007	571573
S16	S10 OR S11 OR S12 OR S13 OR S14 OR S15	1,525,299	1431308
S15	"school age child*" OR "0-11 year* old" OR toddler*	4,914	11094
S14	"young adult" OR "young person" OR "young people" OR pe#diatric* OR teen*	1,239,824	487465
S13	pe#diatric*	1,206,545	185107
S12	infan*	240,804	461067
S11	Adolescen*	257,485	597352
S10	Child*	404,109	856211
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8	6,303	15478
S8	"congenital w3 cardiac"	2,418	8987
S7	"congenital w3 heart"	6,802	18663
S6	ACHD	43	174
S5	guch	7	20
S4	"heart defect*"	5,096	12349
S3	"congenital cardiac disease*"	40	109
S2	"congenital heart defect*"	631	1695
S1	"congenital heart disease*"	2,754	7406

Appendix-II: List of excluded studies from the literature review

Study (Author, year, title)	Reason for exclusion
1. Areias et al., 2013 Long term psychosocial outcomes of congenital heart disease (CHD) in adolescents and young adults	Wrong population
2. Axelrad, 2004 Adaptive Skills, Cognitive, and Behavioral Characteristics of Costello Syndrome	Excluded by title. Wrong population
3. Bellinger, 2008 Are children with congenital cardiac malformations at increased risk of deficits in social cognition?	Full text read Wrong outcome
4. Berant et al., 2008 Mothers' Attachment Style, Their Mental Health, and Their Children's Emotional Vulnerabilities: A 7-Year Study of Children With congenital Heart Disease	Excluded by title and abstract Wrong population
5. BEVILACQUA et al., 2013 Birth of a child with congenital heart disease: emotional reactions of mothers and fathers according to time of diagnosis.	Excluded by title Wrong outcome
6. Boyle, 2015 The School Age Child with congenital Heart Diseass	Full text was read Wrong outcome
7. Brandlistuen et al., 2010 Motor and social development in 6-month-old children with congenital heart defects	Excluded by title and abstract Wrong outcome
8. Brandlistuen et al., 2011 Symptoms of communication and social impairment in toddlers with congenital heart defects	Excluded by title and abstract Wrong outcome
9. Brosig et al., 2007 Neurodevelopmental outcome in preschool survivors of complex congenital heart disease: Implications for clinical practice	Wrong outcome
10. Bruce et al., 2016 Translation and Testing of the Swedish Version of Iceland-Family Perceived Support Questionnaire With Parents of Children With congenital heart defects.	Wrong population
11. Bultas et al., 2015 Psychosocial outcomes of a summer overnight recreational experience for children with heart disease	Full text read Wrong setting
12. Burgess & Swift, 2003 Health-related beliefs and behaviors of adolescents with and without congenital heart disease	Wrong outcome
13. Calderon etal., 2014 Facial expression recognition and emotion understanding in children after neonatal open-heart surgery for transposition of the great arteries	Wrong outcome
14. Cantwell-Bartl. & Tibballs, Place, age, and mode of death of infants and children with hypoplastic left heart syndrome: implications for medical counselling, psychological counselling, and palliative care	Excluded by title. Wrong outcome
15. Cohen at al., 2008 Perceived parenting style, self-esteem and psychological distress in adolescents with heart disease	Wrong outcome
16. Cohen et al., 2007 Quality of Life, Depressed Mood, and Self-Esteem in Adolescents With Heart Disease	Full text was read. Wrong outcome

17. Da silva et al. 2013 Behaviour problems in adolescents with cardiac disease: an exploratory study in a paediatric cardiology outpatient clinic	Wrong population
18. DeMaso et al., 2014 Psychiatric Disorders and Function in Adolescents with d-Transposition of the Great Arteries	Wrong outcome
19. DeMaso et al., 2017 Psychiatric Disorders in Adolescents With Single Ventricle Congenital Heart Disease	Wrong outcome
20. Deng et al., 2016 Prevalence and Correlates of Post-traumatic Stress Disorder in Adults With Congenital Heart Disease	Excluded by title Wrong population
21. Desai et al., 2013 A qualitative study exploring the psychosocial value of weekend camping experiences for children and adolescents with complex heart defects	Wrong outcome
22. Dulfer et al., 2014 Associations between exercise capacity, physical activity, and psychosocial functioning in children with congenital heart disease: a systematic review.	Wrong outcome
23. Freitas et al., 2012 A cohort study on psychosocial adjustment and psychopathology in adolescents and young adults with congenital heart disease	Wrong population
24. Gaynor et al., 2009 Apolipoprotein E genotype modifies the risk of behavior problems after infant cardiac surgery	Wrong outcome
25. Gothelf, 2007 Cognition, psychosocial adjustment and coping in familial cases of velocardiofacial syndrome	Excluded by title and abstract Wrong population
26. Gupta, 2014 Caring for a teen with congenital heart disease	Excluded by title and abstract Wrong outcome
27. Hardoff, 2005 Emotional and behavioral outcomes among adolescents with mild developmental deficits in early childhood	Excluded by title and abstract Wrong population
28. Harrison at al., 2013 Autonomic nervous system function, child behavior, and maternal sensitivity in three-year-old children with surgically corrected transposition	Wrong outcome
29. Jackson et al., 2015 Disease knowledge, perceived risk, and health behavior engagement among adolescents and adults with congenital heart disease	Excluded by title and abstract Wrong outcome
30. Janssens et al., 2016 Exploring the relationship between disease-related knowledge and health risk behaviours in young people with congenital heart disease	Excluded by title and abstract Wrong outcome
31. Janus. & Goldberg,. 1997 Treatment characteristics of congenital heart disease and behaviour problems of patients and healthy siblings	Wrong outcome
32. Karsdorp et al., Psychological and cognitive functioning in children and adolescents with congenital heart disease: a meta-analysis.	Excluded by title Wrong outcome
33. Kendall et al., Factors associated with self-perceived state of health in adolescents with congenital cardiac disease attending paediatric cardiologic clinics	Excluded by title Wrong outcome
34. Kendall, 2007 A simple screening method for determining knowledge of the appropriate levels of activity and risk behaviour in young people with congenital cardiac conditions	Excluded by title and abstract Wrong outcome

35. Knowles et al., 2016 Self-Reported Health Experiences of Children Living with Congenital Heart Defects: Including Patient-Reported Outcomes in a National Cohort Study	Wrong outcome
36. Landolt et al., 2014 Exploring causal pathways of child behavior and maternal mental health in families with a child with congenital heart disease: a longitudinal study.	Wrong outcome
37. Latal et al., 2009 Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: a systematic review	Full text was read. Wrong outcome
38. Lee et al., 2017 The effect of a resilience improvement program for adolescents with complex congenital heart disease	Excluded by title and abstract Wrong outcome
39. Liamlahi et al., 2014 Motor dysfunction and behavioural problems frequently coexist with congenital heart disease in school-age children.	Wrong outcome
40. Limbers et al., Factors associated with perceived cognitive problems in children and adolescents with congenital heart disease.	Wrong outcome
41. LLOPIS, 2014 Parents do suffer: study of stress caused by congenital heart disease in children.	Excluded by title Wrong outcome
42. Lobo & Michel, 1995 Behavioral and physiological response during feeding in infants with congenital heart disease: a naturalistic study	Excluded by title and abstract Wrong outcome
43. Luyckx et al., 2011 Adolescents with congenital heart disease: the importance of perceived parenting for psychosocial and health outcomes.	Wrong outcome
44. Macedo, 2011 The impact of children with congenital heart disease in a family: a literature review	Wrong language.
45. Majnemer & Limperopoulos, 1999 Developmental progress of children with congenital heart defects requiring open heart surgery	Wrong outcome
46. Mari et al., 2012 Anxiety and coping of mothers facing their child's congenital heart disease surgery	Excluded by title Wrong outcome
47. Masi. Adolescents with congenital heart disease: psychopathological implications.	Wrong outcome
48. McCusker et al., 2007 Determinants of neuropsychological and behavioural outcomes in early childhood survivors of congenital heart disease	Wrong outcome
49. McCusker etal., 2012 A randomized controlled trial of interventions to promote adjustment in children with congenital heart disease entering school and their families	Wrong outcome
50. McKechnie, Pridham & Tluczek, 2016 Walking the "Emotional Tightrope" From Pregnancy to Parenthood: Understanding Parental Motivation to Manage Health Care and Distress After a Fetal Diagnosis of Complex Congenital Heart Disease	Excluded by title Wrong outcome
51. Miatton et al., 2007 Neuropsychological performance in school-aged children with surgically corrected congenital heart disease	Wrong outcome
52. MILFORD, 2016 Care of the Family of an Infant With a Congenital Heart Defect During the NICU Hospitalization.	Excluded by title Wrong outcome
53. Molck et al., 2015	Excluded by title and abstract Wrong outcome

8p23.1 Interstitial Deletion in a Patient with Congenital Cardiopathy, Neurobehavioral Disorders, and Minor Signs Suggesting 22q11.2 Deletion Syndrome	
54. Moon et al., Factors influencing depression in adolescents with congenital heart disease.	Excluded by title. Wrong outcome
55. Mussatto et al., 2014 The importance of self-perceptions to psychosocial adjustment in adolescents with heart disease.	Wrong population
56. Norris and Hill, 1992 Assessing congenital heart defects in the cocaine-exposed neonate	Excluded by title Wrong outcome
57. O'Hare, 2014 Social cognition in congenital heart disease: Is this part of adaptive behaviour?	Excluded by title and abstract Wrong outcome
58. Olsen et al., 2011 Congenital heart defects and developmental and other psychiatric disorders: a Danish nationwide cohort study	Wrong outcome
59. Owen et al., 2014 Brain volume and neurobehavior in newborns with complex congenital heart defects	Wrong outcome
60. Prinzie et al., Parenting, family contexts, and personality characteristics in youngsters with VCFS	Wrong outcome
61. Puosi et al., 2011 Neurocognitive development and behavioral outcome of 2-year-old children with univentricular heart.	Wrong population
62. Quadri et al., Art therapy for hospitalized congenital heart disease patients: a method of psychological intervention at the IRCCS Policlinic San Donato Milanese Hospital	Wrong outcome
63. Rassart et al., 2016 A Big Five Personality Typology in Adolescents with Congenital Heart Disease: Prospective Associations with Psychosocial Functioning and Perceived Health	Wrong population
64. Sable et al., 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	Excluded by title and abstract Wrong outcome
65. Sarajuuri et al., 2012 Patients with univentricular heart in early childhood: Parenting stress and child behaviour	Wrong outcome
66. Sarrechia et al., 2015 Neurodevelopmental outcome after surgery for acyanotic congenital heart disease.	Wrong outcome
67. Sarrechia et al., 2015 Neurodevelopment and Behavior after Transcatheter versus Surgical Closure of Secundum Type Atrial Septal Defect	Wrong outcome
68. Sarrechia et al., 2016 Neurocognitive development and behaviour in school-aged children after surgery for univentricular or biventricular congenital heart disease	Wrong outcome
69. Secinti et al., 2017 Research review: Childhood chronic physical illness and adult emotional health — a systematic review and meta-analysis	Wrong population
70. Simons et al., 2007 Decreases in anxiety associated with participation in a camp for children with cardiac defects	Wrong outcome
71. Solberg et al., 2011 Emotional reactivity in infants with congenital heart defects and maternal symptoms of postnatal depression	Wrong outcome

72. SOOD et al., 2016 Developmental Care in North American Pediatric Cardiac Intensive Care Units: Survey of Current Practices	Excluded by title and abstract Wrong outcome
73. Spijkerboer et al., 2008 Long-term intellectual functioning and school-related behavioural outcomes in children and adolescents after invasive treatment for congenital heart disease	Excluded by title and abstract Wrong outcome
74. Spijkerboer et al., 2010 Medical predictors for long-term behavioral and emotional outcomes in children and adolescents after invasive treatment of congenital heart disease	Wrong outcome
75. Struemph et al., 2016 Systematic psychosocial screening in a paediatric cardiology clinic: clinical utility of the Pediatric Symptom Checklist 17	Wrong population
76. Swillen et al. The behavioural phenotype in velo-cardio-facial syndrome (VCFS): from infancy to adolescence.	Wrong population
77. Toren& Horesh Psychiatric morbidity in adolescents operated in childhood for congenital cyanotic heart disease.	Excluded by title Wrong outcome
78. Van Zellem et al., 2016 Cardiac arrest in infants, children, and adolescents: long-term emotional and behavioral functioning	Wrong population
79. Wang et al., 2012 The prevalence and predictors of anxiety and depression in adolescents with heart disease.	Full text was read. Wrong outcome
80. Wei et al., 2016 Parents' experiences of having a child undergoing congenital heart surgery: An emotional rollercoaster from shocking to blessing	Excluded by title Wrong outcome
81. Weiss, 1992 Psychophysiologic and behavioral effects of tactile stimulation on infants with congenital heart disease	Excluded by title and abstract Wrong outcome
82. Wray & Radley-Smith Developmental and behavioral status of infants and young children awaiting heart or heart-lung transplantation.	Excluded by title. Wrong outcome
83. Wray & Sensky, 1998 How dose the intervention of cardiac surgery affect the self-perception of children with congenital heart disease	Wrong outcome
84. Youssef, 1988 School adjustment of children with congenital heart disease	Excluded by title Wrong outcome
85. Zahmacioglu et al., 2011 Coming from behind to win—a qualitative research about psychological conditions of adolescents who have undergone open-heart surgery for single ventricle between the ages 0-5	Excluded by title. Wrong outcome
86. From the update (Oct 2021): Jilek et al., 2021 Predictors of behavioural and emotional outcomes in toddlers with congenital heart disease	Wrong outcome

Appendix-III: Quality appraisal tool (MMAT) used in the literature review

McGill

Mixed Methods Appraisal Tool (MMAT) – Version 2011
For dissemination, application, and feedback: Please contact pierre.pluye@mcgill.ca, Department of Family Medicine, McGill University, Canada.

The MMAT is comprised of two parts (see below): criteria (Part I) and tutorial (Part II). While the content validity and the reliability of the pilot version of the MMAT have been examined, this critical appraisal tool is still in development. Thus, the MMAT must be used with caution, and users' feedback is appreciated. Cite the present version as follows.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., & Rousseau, M.C. (2011). *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews.* Retrieved on [date] from http://mixedmethodsappraisaltoolpublic.pbworks.com. Archived by WebCite® at http://www.webcitation.org/5tTRTc9yJ

Purpose: The MMAT has been designed for the appraisal stage of complex systematic literature reviews that include qualitative, quantitative and mixed methods studies (mixed studies reviews). The MMAT permits to concomitantly appraise and describe the methodological quality for three methodological domains: mixed, qualitative and quantitative (subdivided into three sub-domains: randomized controlled, non-randomized, and descriptive). Therefore, using the MMAT requires experience or training in these domains. E.g., MMAT users may be helped by a colleague with specific expertise when needed. The MMAT allows the appraisal of most common types of study methodology and design. For appraising a qualitative study, use section 1 of the MMAT. For a quantitative study, use section 2 or 3 or 4, for randomized controlled, non-randomized, and descriptive studies, respectively. For a mixed methods study, use section 1 for appraising the qualitative component, the appropriate section for the quantitative component (2 or 3 or 4), and section 5 for the mixed methods component. For each relevant study selected for a systematic mixed studies review, the methodological quality can then be described using the corresponding criteria. This may lead to exclude studies with lowest quality from the synthesis, or to consider the quality of studies for contrasting their results (e.g., low quality vs. high).

Scoring metrics: For each retained study, an overall quality score may be not informative (in comparison to a descriptive summary using MMAT criteria), but might be calculated using the MMAT. Since there are only a few criteria for each domain, the score can be presented using descriptors such as *, **, ***, and ****. For qualitative and quantitative studies, this score can be the number of criteria met divided by four (scores varying from 25% (*) -one criterion met- to 100% (****) -all criteria met-). For mixed methods research studies, the premise is that the overall quality of a combination cannot exceed the quality of its weakest component. Thus, the overall quality score is the lowest score of the study components. The score is 25% (*) when $QUAL=1$ or $QUAN=1$ or $MM=0$; it is 50% (**) when $QUAL=2$ or $QUAN=2$ or $MM=1$; it is 75% (***) when $QUAL=3$ or $QUAN=3$ or $MM=2$; and it is 100% (****) when $QUAL=4$ and $QUAN=4$ and $MM=3$ (QUAL being the score of the qualitative component; QUAN the score of the quantitative component; and MM the score of the mixed methods component).

Rationale: There are general criteria for planning, designing and reporting mixed methods research (Creswell and Plano Clark, 2010), but there is no consensus on key specific criteria for appraising the methodological quality of mixed methods studies (O'Cathain, Murphy and Nicholl, 2008). Based on a critical examination of 17 health-related systematic mixed studies reviews, an initial 15-criteria version of MMAT was proposed (Pluye, Gagnon, Griffiths and Johnson-Lafleur, 2009). This was pilot tested in 2009. Two raters assessed 29 studies using the pilot MMAT criteria and tutorial (Pace, Pluye, Bartlett, Macaulay et al., 2010). Based on this pilot exercise, it is anticipated that applying MMAT may take on average 15 minutes per study (hence efficient), and that the Intra-Class Correlation might be around 0.8 (hence reliable). The present 2011 revision is based on feedback from four workshops, and a comprehensive framework for assessing the quality of mixed methods research (O'Cathain, 2010).

Conclusion: The MMAT has been designed to appraise the *methodological quality* of the studies retained for a systematic mixed studies review, not the quality of their *reporting* (writing). This distinction is important, as good research may not be 'well' reported. If reviewers want to genuinely assess the former, companion papers and research reports should be collected when some criteria are not met, and authors of the corresponding publications should be contacted for additional information. Collecting additional data is usually necessary to appraise *qualitative research and mixed methods studies*, as there are no uniform standards for reporting study characteristics in these domains (www.equator-network.org), in contrast, e.g., to the CONSORT statement for reporting randomized controlled trials (www.consort-statement.org).

Authors and contributors: Pierre Pluye[1], Marie-Pierre Gagnon[2], Frances Griffiths[3] and Janique Johnson-Lafleur[1] proposed an initial version of MMAT criteria (Pluye et al., 2009). Romina Pace[1] and Pierre Pluye[1] led the pilot test. Gillian Bartlett[1], Belinda Nicolau[4], Robbyn Seller[1], Justin Jagosh[1], Jon Salsberg[1] and Ann Macaulay[1] contributed to the pilot work (Pace et al., 2010). Pierre Pluye[1], Émilie Robert[5], Margaret Cargo[6], Alicia O'Cathain[7], Frances Griffiths[3], Felicity Boardman[3], Marie-Pierre Gagnon[2], Gillian Bartlett[1], and Marie-Claude Rousseau[8] contributed to the present 2011 version.

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PART I. MMAT criteria & one-page template (to be included in appraisal forms)

Types of mixed methods study components or primary studies	Methodological quality criteria (see tutorial for definitions and examples)	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	• Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?				
	• Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).				
	Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?				
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?				
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?				
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?				
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?				
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?				
	2.3. Are there complete outcome data (80% or above)?				
	2.4. Is there low withdrawal/drop-out (below 20%)?				
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?				
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?				
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?				
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?				
	4.2. Is the sample representative of the population understudy?				
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?				
	4.4. Is there an acceptable response rate (60% or above)?				
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?				
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?				
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?				
	Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.				

*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

Appendix-IV: Participants information sheet (PIS)- for parents

You are invited to take part in the above named study but before you decide, please read the following information.

What is the purpose of this study?

This study is investigating the behaviour and emotions of children aged 4-10 years with congenital heart diseases. It aims to hear the children's perceptions about their own behaviour and emotions and how do their parents perceive their behaviour and emotions as well. It is expected that the results of this study will help the healthcare providers to gain new knowledge and to pay more attention toward the behaviour and emotions of these children and their parents in Saudi Arabia.

Who is doing the study?

This study is being undertaken by Nada Dahlawi as part of her PhD studies supervised by Professor Veronica Swallow and Dr Linda Milnes at the School of Healthcare, University of Leeds, Leeds, United Kingdom.

Why have I been asked to participate?

You are being approached because you are a parent of a child who is diagnosed with congenital heart disease, in the age group of 4-7-year olds, admitted to paediatric medical and surgical wards at Hospital in Jeddah, Saudi Arabia.

What will be involved if I take part in this study?

You will be interviewed by the researcher Nada Dahlawi about how you perceive the behaviour and emotions of your child. You will also be asked to give approval for the researcher to interview your child to get the child's self-perception about their own behaviour and emotions. It is suggested to

interview the child individually but you will be given the choice to accompany the child during the interview if you wish that. The child will be asked to draw and describe the drawing to help the child to engage during the interview. The interview will take no more than one hour of your time, will be audio-recorded and will take place at the ward's activity room in the hospital. The researcher will also write some notes (called field notes) about the environment and how busy it is.

What are the advantages and disadvantages of taking part?

Your and your child's views will help us to understand the behavioural and emotional status of children with congenital heart disease. Also, this study will help the healthcare providers to develop future plans for preventative and supportive measures to be provided to children with congenital heart disease and their parents, including you and your child.

Can I withdraw from the study at any time?

You and your child can withdraw from the study at any time (before the date 29 Feb 2020 when the study will be submitted to the university and/ or publication is in process) without needing to give a reason. Your child's treatment will not be affected by your decision about participation.

Will the information I give be kept confidential?

All information given by you and your child will be kept confidential. Your and your child's names will be removed from the interviews transcripts which means only the researcher and the researcher's supervisors will have access to the interviews, audio-recorder and the field notes for the purpose of data analysis. However, child's interviews confidentiality will have to be broken in case of detection of any signs of abuse or other illnesses that were detected during the interviews that needed to be reported to the healthcare providers.

What will happen to the results of the study?

All participants' responses will be analysed. Some quotation of participants responses will be displayed in the results part of the study to illustrate the views of the participants. However, these quotations will not be associated with your or your child's names. The results of this study will be presented in a scientific journal and at a conference. Upon request, you can receive a copy of the study results.

Who has reviewed this study?

Ethical approval has been granted by the School of Healthcare Research Ethics Committee at the University of Leeds and by the Research Ethics Committee at the hospital in Jeddah.

If you agree to take part, would like more information or have any questions or concerns about the study please contact:

Nada Dahlawi	*Professor Veronica Swallow*	*Dr Linda Milnes*
PhD student	*Chair in Child and Family*	*Associate Professor*
Baines Wing	*Healthcare*	*Baines Wing*
University of Leeds	*Baines Wing*	*University of Leeds*
LS2 9UT, Leeds, UK	*University of Leeds*	*LS2 9UT, Leeds, UK*
Tel: +966 546520099	*LS2 9UT, Leeds, UK*	*Tel: 0113-343-1342*
Email: hcnad@leeds.ac.uk	*Tel: 0113-343-1384*	*Email: L.J.Milnes@leeds.ac.uk*
	Email: V.M.Swallow@leeds.ac.uk	

Thank you for taking the time to read this information sheet..

Participants Information Sheet

(Children 6- 10 years old)

- **What is research? Why is this project being conducted?**

Research is a way of finding an answer to questions.

We want to see if congenital heart disease affects the
behaviour and emotions of children.

- **Why I have been asked to take part?**

You were chosen to take part because you are a patient at King Abdul-Aziz
University Hospital. The project will involve other patients like you. If you will
agree to take part, your parents will join as well.

- **Did anyone else check the study is ok to do?**

This research has been checked by a group of people called a Research Ethics
Committee. They make sure that the research is ok to be done. This research
has been checked by the ethics committee at University of Leeds in UK and the
ethics committee at King Abdul-Aziz University Hospital in Jeddah, Saudi
Arabia.

- **Do I have to take part?**

It is up to you to decide to take part in this research. Your treatment at the
hospital will not be changed if you decide not to take part.

- **What will happen to me if I take part in the research?**

You will be asked some questions that will help me to understand your emotions and
behaviour. You will be joining in activities like, drawing, play and storytelling. I will
record your answers using a recorder to help me listen to your answers carefully
afterwards. I will also need to write some notes from time to time during the
activities.

- **Will joining in help me?**

Your answers will help me understand how you feel about your heart condition. I will not tell the doctors and nurses your name or the name of any child who talks to me, but I will add up the answerers from all children to share with the doctors and nurses. This will help them to know the best way to talk to children like you and their parents.

- **Will anyone know what I have said or done during the interview? Will anyone know I'm doing this?**

No one will know what you have answered or that you took part in the research or not. Your name will be removed from the interview papers and only me and my supervisors will need to know your name. But if I found out that you are hurt or sick and you need help, then I will need to help you by telling the doctor about you and your name.

- **What if I do not want to do the research anymore?**

You can go out of the research at any time and you do not need to give me reason for that. You can go out at any time before I give my project to my school on 29 Fb 2020. Your treatment will be the same even if you decide to go out of the research.

Thank you for taking the time to read this information sheet.

If you want to take part, and need more information please contact me:

Nada Dahlawi

PhD student

Baines Wing

University of Leeds

LS2 9UT, Leeds, UK

Tel: +966 546520099

Email: hcnad@leeds.ac.uk

Professor Veronica Swallow

Chair in Child and Family Healthcare

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Appendix-V: Modified interview topic guide

Participants	Interview Topic
Children	1) Welcome the child, thank the child for participating, introduce myself. Reassure that the parents have the choice to attend their child's interview.
	2) Discuss ethics: assent, confidentiality limitations, and audio recording. Invite the child to ask questions.
	3) Warming up: Getting the child to talk. Describe the play or the activities. 1. Do you want me to call you by your nick name? How old are you? 2. What is your favourite colour? 3. What is your favourite game?
	4) Feeling toward self and heart condition: 1. Can you draw yourself ? Ask what this child looks like? Feels (introduce emojis or pictures of emotions to pick up from)? What is this child thinking about? 2. What are the things you like about yourself? What are the things you don't like about yourself? Tell me more about yourself? Do you think you are smart? Beautiful? Why? 3. Can you draw your heart? What does your heart looks like? Why? 4. Can you draw yourself before and after being sick? How do you look like? 5. (Show the child pictures of hearts with different colours) Which of these is your heart? Why? Describe the heart you pick? How it is different than the other hearts? 6. (Show picture of hospital, medicine and doctors) Can you tell me what is building? What does this person (doctor) do? When you see this pictures what do you feel (pictures of emotions)? 7. Can you draw me the hospital that you go to? Describe it? Do you like it? Why? 8. Can you draw your doctor? How does he look like? Do like your doctor? Why? **Additions:** **9. If you are going to discuss your condition/ or feeling with your friends, what would you tell them?** **10. How did you feel before and after the heart surgery? (probing questions)**
	5) Self-perception towards their behaviour and emotion: 10. Can you draw your house? Who lives in this house? Do like your house? What do you usually do at home to spend time? 11. Can you draw your mother and father? Do love them? Why? Do you play with them? What do you love to do with them? Do you listen to what they tell you to do? Tell me more about it? What do you feel when they ask you to do things (pictures of emotions)? 12. Can you draw your siblings? Which one is your best? Why? Do you like to play together? Why? **(Additions): Do you get jealous of your siblings? How do you feel if parents or others are taking care of your siblings?** 13. Do you think your family loves you? Why? Does anything make you upset or sad at home? What is it? 14. What are the things make you happy? 15. What are things make you sad? 16. Do you cry a lot? Tell me more about it? 17. Is there anything you afraid of? Tell me more about it? 18. Do get angry all the time? What makes you angry? 19. Do you think you have special ideas or thoughts? Like what? **Additions:** 20. **Tell me more about what do you mean by being angry and crying (if the child mention them).**
	6) School activities and socialisation: 1. Do you go to school? What grade? 2. Can you draw your school? Do you like your school? Tell me about your school. How are your grades? 3. Do have friends at school? How many? Do you like them? Do they like you? Tell me more about it?

	4. Do you feel that you are different than them? Tell me more about it? 5. Does anyone / anything bother you at school? Tell me more about it? 6. Do you think that people like you? Tell me more about it? 7. Do you like to stay alone or with people? Tell me more about it? 8. Are there any activities you are joining at school or outside school? Do like these activities? Tell me more about it? 9. Is there any place that you enjoy visiting? Why do you like this place? **Additions:** **10. Did you tell your friends or others about your condition? why?** **11. Have you ever talked to other children who have same heart condition? Tell me more about it? How would you feel if you tell anyone? Tell me more about it?** **12. Do you enjoy playing and running? Where do you play and with whom? How do you feel when playing? What do you do if feeling tired? How do you feel about being tired?** **13. (if having speech or recall issues): How do you feel about having this difficulty? Tell me more.**
	7) Coping and support: 1. You told me that you have heart condition? how do you fell about it? Tell me more about it? 2. Do you think it will be useful to talk to doctors and nurses about the things that bother you? **Additions:** **3. Do the doctor talk to you about your condition?** **4. Did your parents or other people explain the condition to you?**
	8) Closing and offering time for questions: 1. Thank you very much to talk to me 2. Is there anything you want to tell me about before leaving? 3. Do you have any questions?
Parents	1) Welcoming: Welcome the parents, thank them for their participation, introduce myself. Reassure that they have the choice to be interviewed separately or jointly.
	2) Discuss ethics: Take consent, restate what is this research about and the aim of conducting it, assure confidentiality, the need for recording. Invite parents to ask questions.
	3) Warming up and parent's awareness about their children's condition: (10 min) 1. Tell a little bit about your family. Nationality, years of stay in Saudi Arabia (if not Saudi), when have you immigrated to Saudi Arabia (if immigrated) number of children , other children with CHD, age and occupation. 2. Tell me about your child? 3. How do you describe your child's health condition? 4. What do you know about CHD? When your child was diagnosed? What is his treatment plan? **Additions:** **5. At what age your child have been diagnosed and received treatment? was it in Saudi Arabia?** **6. Is your child aware of his condition? How did your child become aware of the condition? Tell me more? How do you feel about your child being aware of the condition?- If the child is unaware: tell me more about your child not knowing about the condition? Tell me more about not wanting your child to know? What does it make you feel? What makes you keep your child unaware of the condition?** **7. Other people would not want their children to know about their conditions. What do you think about that?**
	4) Perception on children's behaviours and emotions: (25 min) 1. How do your child behave at house? Behave with you? With siblings? 2. What concerns you the most about your child? Why ?

3. What is the best quality in your child? Tell me more. **Addition: other parents would say their child with CHD is so caring and soft-hearted, what do you say about that? Why do you think your child have this quality?**

4. How do describe your child's emotions? Give me examples- describe more. **Additions: does your child express his/her feelings? Tell me more. How? What are your child's emotions toward you? How is your relationship? How do you spend time together?**

5. How do you describe your child's behaviour? Give me examples- describe more.

6. Have you noticed your child with any strange behaviour? Describe what are they? Why do you think your child is having behaving like this? Tell me more.

7. Have you noticed your child with strange thoughts or idea? Describe what are they? Why do you think your child having these thoughts?

8. Can you tell me how was your child before and after the diagnosis of heart condition? **Addition: did you notice any change in behaviour and emotions over time?**

9. How are you dealing with these changes? Do you think that dealing with your child with your mentioned way is effective? Why? Do you think you can dealing with your child differently towards these issues/changes in your child? Describe more?

10. How does your child feels towards the hospital? Seeing a doctor or a nurse? Why do you think he is feeling this way? **Addition: does you child express these feelings?**

11. How does your child feels towards the heart condition? Tell me more. **Addition: how does your child feel and behave before and after the treatment?**

12. Does your child cries often? What makes him cry? How do you react when he/she does?

13. Does your child get angry easily? What makes him angry? How do react toward his anger?

14. How does your child react toward your rules and disciplines? Why do you think he reacting this way?

15. Do you think your child seeks attention? Why do you think that?
Addition:

16. **Do you think that you child act to get special treatment from you or others? How? Does your child mention being ask and eligible to get special treatment? Why you think he/she reacting this way? Give me examples.**

5) Perceptions children's school activities and socialisation: (15 min)

1. How is your child's performance at school? Grade?

2. How does your child behave at the kindergarten/school? How do the teachers describe your child behaviour at school? Why do you think they describing your child this way?

3. Does your child have friends? At school or outside the school? How many? Close friends? How do your child treat his/her friends?

4. How do you describe your child's social interaction? Do you describe him as an isolated child or social child? Why do you think he is like that?

5. Does your child have activities/hobbies inside or outside the school? What are they?

6. Do you think your child enjoyed these activities and hobbies? Tell me more

7. How do you describe your child's physical activities in general? Tell me more
Additions:

8. **Does the school know about your child's condition? what do you feel about telling the school about your child's condition?**

9. **Do you think your child behaviour and emotion at school are similar to what they are at home? Tell me more.**

10. **Does your child feel jealous of their siblings? Why do you think is that? How would you describe your child's relationship with the other siblings?**

11. **How do you think about your parenting style? Would you do anything different?**

12. **Do you try to discipline or correct your child's behaviour? How do you feel if scold your child? How does your child react? Tell me more**

| | | 6) Coping and support: (10 min)
1. Do you think that there things that you can do to minimize the changes in your child's behaviour and emotions? What are they? Why?
2. How do you describe your child coping mechanism with the disease?
3. What do you think of having family support for families of a child with CHD? Tell me more.
Addition:
4. Does the doctor or nurses explain the condition to your child? How do you feel about that?
5. Have you or your child ever been referred to psychiatric or social consultation or support?
6. What do you feel about how much you know about your child's condition? Do you need to learn more? What are your resources to get information about the condition?
7. Other parents might say they don't want to know about their children's condition to avoid being too anxious. What do you think about that? |
| | | 7) Closing and offering time for questions: (5 min)
1. Is there anything you want add about your child's behaviour and emotions?
2. Do you have any questions?
3. Thank you very much for your time |

Appendix-VI: Example of the initial coding sheet

Appendix-VII: Examples of memo's diagrams and tables

Comparisons of findings from literature review and findings from my research:

Similar findings	Different/ opposed findings

Findings from the literature review	**Findings from GT**
All CHD severities	All CHD severities
Behavioural and emotional issues in CYP with CHD: Studies with only parents reports: • Internalizing behavioural issues in children (4-13 years old) Studies combined child and parents perceptions: • Child- parent disagreement: In study: parents reported more behavioural and emotional issues than children reported themselves. Other studies: CYP reported themselves with more problems than their parents perceived them. Explanation by reviewed study (but needs investigations): unaware parents- or parents did not want to face child's sickness- protective parents- child's denial – live a normal life • A group of parents of healthy children and group of parents of CHD children compared their children (maybe irrelevant?- no comparison to healthy group was done in current research) • Comparisons of CHD children with healthy children in exhibiting behavioural and emotional issues (maybe irrelevant? In the current GT comparison was done in physical activity only)	The interview topics was guided by Children Behavioural checklist, which was used in the most of the reviewed studies. Qualitatively, children and parents were asked about things that indicate the existance of behavioural and emotional issues • Children reported issues as much as their parents did • Some parents reported their children being "so normal" • Some children denied having CHD • Parents protection: keeping the child unaware • Children with CHD got tired more easily than healthy children

Appendix-VIII: Participants consent form- parents

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School of Healthcare

Participant Consent Form (Parents)

Perception of children aged 4-10 years old with congenital heart disease in Saudi Arabia and their parents' reports on the children's behaviour and emotions

	Please confirm agreement to the statements by putting your initials in the box below
I have read and understood the participant information sheet	
I have had the opportunity to ask questions and discuss this study	
I have received satisfactory answers to all of my questions	
I have received enough information about the study	
I understand that my child will participate and will be interviewed	
I understand that I am free to withdraw from the study:- 1 At any time/up to 29 Feb 2020 (before the submission of the study) 2 Without having to give a reason for withdrawing 3 Any information already provided by the participant will be discarded and will no longer be used for the research purposes following withdrawal from the study.	
I understand that my interview will be audio-recorded.	

I understand that any information I provide, including personal details, will be kept confidential, stored securely and only accessed by those carrying out the study.	
I understand that any information I give may be included in published documents but all information will be anonymised.	
I agree to take part in this study	
Participant Signature …………………………………………………	Date
Name of Participant	
Researcher Signature …………………………………………………..	Date
Name of Researcher	

Appendix-IX: Participants verbal consents form- parents

With permission this verbal consent process will be recorded and transcribed.

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Title of Study: Perception of children aged 4-10 years old with congenital heart disease in Saudi Arabia and their parents' reports on the children's behaviour and emotions

Participant's name: …………………………

I am Nada Dahlawi, PhD student at the School of Healthcare, University of Leeds, United Kingdom. Thank you for agreeing to be contacted and to be interviewed for my PhD research.

My research is conducted to understand the behaviour and emotions of children aged 4-10 years with congenital heart diseases. It aims to hear the children's perceptions about their own behaviour and emotions and how do their parents perceive their behaviour and emotions as well. This research will help healthcare providers to gain new knowledge and to pay more attention toward the behaviour and emotions of these children and their parents in Saudi Arabia.

I am asking you to participate in an individual telephone interview which will take about an hour. Taking part is voluntary and if you decide you do not wish to participate you may withdraw at any time, before the date 29 Feb 2020 (when the study will be submitted to the university and/ or publication is in process). The discussion we have will be anonymised – any reference to your name, or other identifying details will be removed from the recordings. Moreover, the telephone interview will be done in a private locked room to ensure that the discussion will not be overheard. We will assign you a participant number and your name will not appear in any report arising from this study. The transcribed data will be used for quotations in presentations and publications but they will be anonymous.

There are not any risks in taking part in this interview and by taking part you are consenting to participate.

I have already sent you a copy of this script, participant's information sheet, and the consent form.

I am now going to take you through a series of questions to guide us through the verbal consent process.

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	Agreement to the statements (delete as required)	
I have read and understood the participant information sheet (If 'no' – record the question here and discuss before establishing consent)	Yes	No
I have had the opportunity to ask questions and discuss this study (If 'no' – record the question here and discuss before establishing consent)	Yes	no
I have received satisfactory answers to all of my questions (If 'no' – record the question here and discuss before establishing consent)	Yes	No
I have received enough information about the study (If 'no' – record the question here and discuss before establishing consent)	Yes	No
I understand that my child will participate and will be interviewed	Yes	No
I understand that I am free to withdraw from the study:- At any time/up to 29 Feb 2020 (before the submission of the study) Without having to give a reason for withdrawing Any information already provided by the participant will be discarded and will no longer be used for the research purposes following withdrawal from the study.	Yes	No
I understand that my interview will be audio-recorded. (If 'no' – record the question here and discuss before establishing consent)	Yes	No
I understand that any information I provide, including personal details, will be kept confidential, stored securely and only accessed by those carrying out the study. (If 'no' – record the question here and discuss before establishing consent)	Yes	No
I understand that any information I give may be included in published documents but all information will be anonymised. (If 'no' – record the question here and discuss before establishing consent)	Yes	No
I agree to take part in this study	Yes	No

Name of Participant	
Participant's verbal consent	Yes No
Date	
Name of researcher	

Researcher's signature	
Date	

Do you consent to the telephone interview now proceeding?   Yes   No

Appendix-X: Children's assent form

To be completed by the child with assistance of their parents. Children younger than 6 years will be given verbal instructions to circle their answers with the assistance of their parents.

Project name: Children's Behaviour and Emotions

Child to circle all they agree with:

Do you understand what this project is about?

Have you asked all the questions you want?

Have you had your questions answered the way you understand?

Are you happy to take part?

If any answer is "NO" or you do not want to take part, do not sign your name below..

If you do want to take part, write your name below:

Your Name: …………………………………………….

Date: ………………………………………………….

Then, your parents will sign:

Parent's name: ………………………………………….

Parent's signature: ……………………………….

Date: ………………………………………………….

The researcher has to sign as well:

Researcher's name: ………………………………

Sign: ………………………………………………….

Date: ………………………………………………….