INVESTIGATION OF OVERPROTECTION IN PEDIATRIC CARDIOLOGY

TU Delft

Erasmus MC
Universitair Medisch Centrum Rotterdam

Delft University of Technology
Faculty of Industrial Design Engineering
Master thesis by **Yun-Jung Tsai**

“Living is a process of developing oneself. Without experiencing pain from disconcerting periods of our lives, we would be different person, perhaps a lesser person.”

— Kilroy J. Oldster, Dead Toad Scrolls

Investigation of overprotection in pediatric cardiology

Yun-Jung Tsai
4736508

Master Thesis
MSc. Strategic Product Design
Industrial Design Engineering
Delft University of Technology

Supervisory Team
Delft University of Technology
Chair: Dr. ir. Maaike Kleinsman
Mentor: Ir. Ruud van Heur

Sophia Children's Hospital, Erasmus MC
Mentor: Arend Van Deutekom

TU Delft

Erasmus MC
University Medical Center Rotterdam

ACKNOWLEDGMENT

Looking back the past few months, it was a rugged journey full of challenges as I dived into the unfamiliar and unfathomable ocean of cardiology and parenting behavior. I would like to express my appreciation to all those who either encouraged me to dive deeper or gave me a hand when I felt drowning.

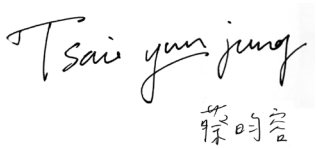
First of all, I would like to thank my supervisors, Maaike, Ruud, and Arend, for professional knowledge in the fields of design and cardiology, as well as patiently guidance that nudged me toward a higher level of expertise.

Next, I would like to thank Max van Manen for assisting me conducted the empirical research, and explaining all my questions regarding language and Dutch culture.

Thanks to all my friends who accompanied me through the journey. In particular, I would like to thank Gu, YeeJek, and Yiting for valuable advice on the project. Also, thanks to Justine, Flora, Kelly, and Lun for mental support that released my stress.

I especially want to thank my lovely family, and my best partner ever, Kuan-Wei Wu. Thank you for consoling my sorrow and confused, also encouraging me to move forward. Without your strong and steady support, I could not have gone through the journey.

Last but not least, I want to show my highest appreciation and respect to all those who participated in my empirical research. Thank you for sharing your invaluable story with me. The whole research would not be possible without your participatory.



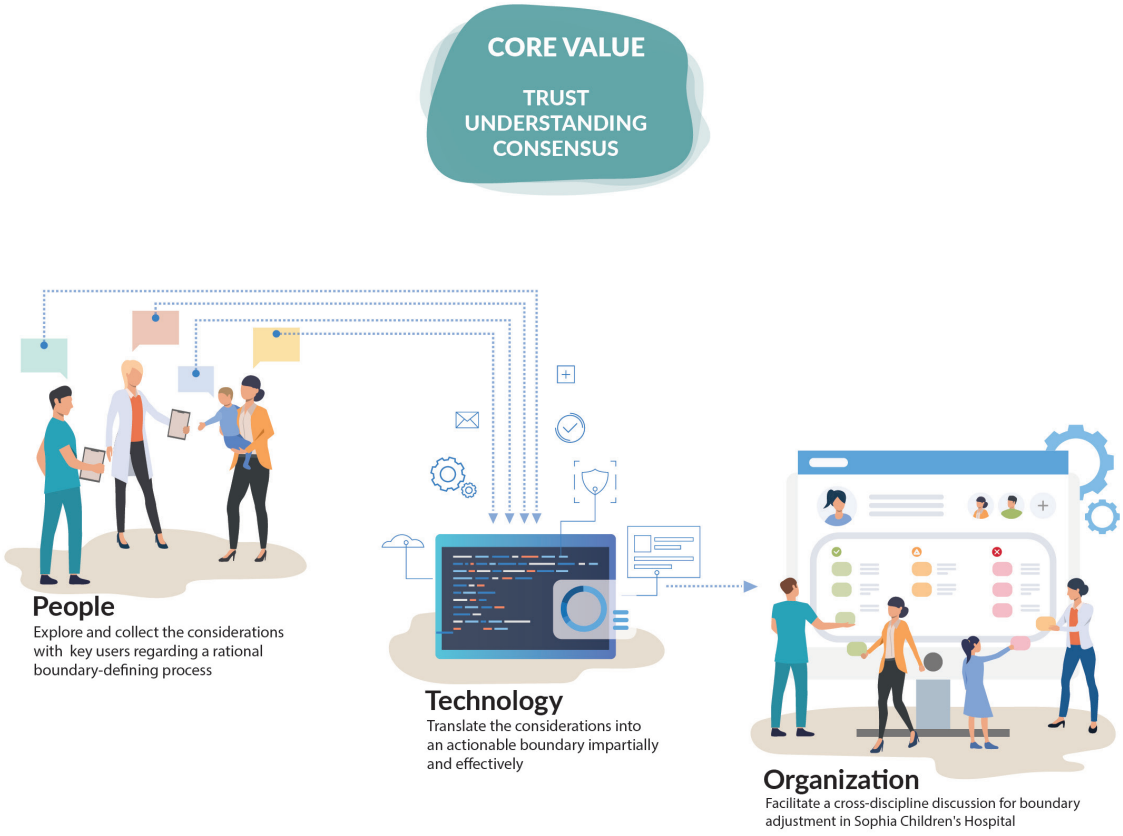
Yun Jung Tsai
10/2019

EXECUTIVE SUMMARY

Humanity grows from making mistakes. However, there is a group of people, and their cost of mistakes might be higher than the average. They are therefore protected by others, and their opportunity to explore the world is deprived. This protective behavior could be unnecessary or excessive, which is defined as *overprotection*. To detect the overprotection issue in the field of pediatric cardiology, the researcher, together with Erasmus MC- Sophia Children's Hospital, set up a collaborative program. The ultimate goal of the program was to design a smart product-service system which can prevent overprotective behavior in children with congenital heart disease.

The present thesis is the initial step of the collaborative program— investigation of overprotection in pediatric cardiology. It addresses the concept of overprotection (OP) and vulnerable child syndrome (VCS), studies on the health-related life of children with congenital heart disease (CCHD), and their parents (PCCHD), then proposes a reformulated design goal and three tangible design missions as the final result.

In the literature review, theoretical knowledge of overprotection and vulnerable child syndrome is elaborated. Three factors are especially highlighted, respectively risk factor, challenge, and indicator. The risk factor indicates the



event that may trigger overprotection development; challenge means the parental barrier of performing proper protection; indicator expresses the theoretical assessment of overprotection. These factors are further brought to the empirical study to see how they influence life of CCHD and PCCHD.

Empirical insights are captured during the empirical study. A total number of eight interviews were conducted, and the researcher also attended a sharing event in which five CCHD gave speeches on their grown-up experience. Collecting the medical history, interaction with people around, and narratives or opinions about overprotection was the main purpose of the empirical study. Factors derived from the literature were continuously reflected and compared with the empirical data.

Theoretical knowledge and empirical insights were further integrated and synthesized. Based on the empirical narratives, the applicability of the theoretical overprotection indicators in pediatric cardiology is evaluated. Two indicators are found to have the highest significance and thus are suggested as the prioritized behavior that needs to be prevented. In addition, extreme quotes and narratives are selected and formulated in a positive case and a negative case. The positive case indicates good patient-parent relation without overprotection reported, while the negative case means tension in patient-parent relation with overprotection reported. Each case contains a patient persona, a parent persona, a health journey map, and an interactive map. Besides discerning the existing factors, four beneficial triggers are generated and highlighted as the main determinants which contribute to the difference between the positive case and the negative case. The insights provide a hint for potential design directions— prevent risk factors, support users to overcome the challenges, and guide users toward the beneficial trigger.

Based on the design directions, a reformulated design goal and three corresponding design briefs were proposed as the final result of the thesis. The design goal was framed as "Design a product-service system which facilitates rational discussions within children with congenital heart disease, their parents and medical experts, to achieve a consensus upon diagnosis-specific and personalized boundaries between proper-protection and overprotection." The three design briefs are further written as three dependent design assignments that provide guidelines and suggestions to the following designers.

Reading guidelines

Content made **bold and in red** is important information highlighted.

Content made *italic and in green* is the original quote from the interviews and speeches.

Content framed in grey is the extra reading supplement that provides elaboration of concepts discussed.

Abbreviations used

CHD- congenital heart disease
CCHD- children with congenital heart disease
PCCHD- parents of children with congenital heart disease
OP- overprotection
VCS- vulnerable child syndrome

TABLE OF CONTENT

1 INTRODUCTION

This chapter starts with the introduction of the graduation assignment. Also, the background knowledge of congenital heart disease, and the target issue—overprotection is addressed.

This graduation assignment is part of a collaborative program of the Pediatric Cardiology Department of Erasmus MC- Sophia Children's Hospital, and the faculty of Industrial Design Engineering (IDE) of Delft University of Technology.

With existing literature and working experience in Sophia Children's Hospital, the researcher saw that children with congenital heart disease (CHD) are overprotected by people around them. People could overprotect these children unintentionally because of the fear that something bad will happen. However, overprotective behavior is believed to hinder healthy child development. Therefore, the researcher set up the collaborative program, aiming for a solution that can support caregivers of children with CHD (CCHD) to avoid overprotection and ensure the relatively normal lives of these children. **The graduation assignment is the initial investigation of the collaboration program, aiming to construct a better understanding of the lives of children with CHD and the overprotective behavior of their caregivers.**

After the background story behind the initiation of the graduation assignment presented above, a brief introduction to congenital heart disease and overprotection will be addressed.

Afterward, this set of information will be brought forward to introduce the purpose of the assignment, the research scope, and design approach.

1-1.
Congenital heart disease (CHD)

The term "congenital" indicates the condition is developed before birth, and heart disease means the heart, or the vessels near the heart, do not develop as normal. According to the American Heart Association, congenital heart disease (CHD) is the most common type of birth defects, it affects 8 out of every 1000 newborn babies ("Understand Your Risk for Congenital Heart Defects", 2019), and is now estimated to be the second most prevalent chronic illness for children (Singh, 2017).

Congenital heart disease (CHD) can be diagnosed with fetal echocardiography, a special ultrasound that normally is conducted around 18 to 22 weeks of the pregnancy. However, some mild heart defects can only be detected after birth or even several years after. Epidemiological studies have suggested that a genetic or environmental cause can be identified in 20% to 30% of CHD cases (Cowan & Ware, 2015). Some behaviors are also believed to increase the risk of CHD, such as smoking, drinking or having certain infections during pregnancy.

The common symptoms, particularly happened in young patients, including rapid heartbeat and breathing, cyanosis (skin turns in blue), swelling legs or around eyes, tiredness, or even fainting during exercise. Besides, patients with CHD have increased risk of respiratory tract infections (RTIs), endocarditis, pulmonary hypertension, and developmental problems. These could have a huge impact on patients' life, growth, and development.

Fortunately, with early diagnosis and advanced surgical techniques, 90% of children with CHD can survive into adulthood (Warnes, 2005). While the disease is not considered fully curable yet, patients with CHD often can be restored to most of their heart function with modern medical techniques. Many of these patients still continuously confront various biopsychosocial issues such as body image concerns and delay in social maturation (Kovacs et al., 2005), and a lower level of health-related quality of life is reported among children and adolescents with CHD (Uzark et al., 2008).

CHD influence on the life of patients

Physical limitations, caused by heart dysfunction or insufficient training, is a factor that contributes to the low health-related quality of life (Marino et al., 2012). It is consistent with the argument of Dahan-Oliel, Majnemer, and Mazer (2011) that physical limitation, irrespective of actual or perceived, is positively correlated with a low quality of life.

Besides, for school-age children with CHD, the inescapable absence at school, owing to hospital visits or surgical operations, interrupt their learning process. These children might spend extra effort to catch up with school assignments. Special needs and body features, such as scars or pectus excavatum, could bring embarrassing

dynamics with peers and even lead to isolation or bullying.

Moreover, heart-focused anxiety, a distinctive mental issue of cardiac patients, is also reported as risk factors of low health-related quality of life and depression (Hoyer et al., 2008). Heart-focused anxiety is defined as "a fear of heart-related symptoms and sensations precipitated by perceived negative consequences associated with cardiac-related sensations" (Eifert et al., 2000). It happened significantly among patients undergoing cardiac surgery. Collectively speaking, even when the heart disease is cured or palliated, the lives of CCHD are still compromised to an unignorable extent.

CHD influence on the life of parents

Congenital heart disease not only influences the life of patients but also the people around them. A significant number of studies have shown a negative impact on the parents of children with CHD (PCCHD).

PCCHD are believed to be at high risk for psychosocial problems. An increased sense of isolation, a loss of social support and an increasing financial burden among PCCHD have been recognized (Gregory et al., 2018). Negative emotional experiences such as guilt, fear, anger, and hopelessness are pervasive among PCCHD (Lawoko & Soares, 2006), and reported a higher level than the parents of children with other diseases (Gregory et al., 2018). Besides, mothers might blame themselves for not having a healthy infant (Bruce, Lilja & Sundin, 2014). For those who have multiple children, neglecting healthy children is also reported (Singh & Ghimire, 2017). Moreover, a study of children with medical disorders showed that the severity of illness is positively correlated to parents' stress level, and may influence parenting behavior (Ungar, 2009).

1-2. Overprotection as the target issue

The grow-up experience of children with CHD (CCHD) is different from those of healthy peers, even though sometimes there is not a medical reason to treat them differently. According to a study that invited 142 PCCHD to participate, difficulty exists in parental difficulty in discerning the appropriate discipline or limitation of children with CHD is proposed (Singh & Ghimire, 2017). The reason for this is that the informal caregivers (e.g. parents or teachers) hold the fear that something bad will happen with the child if they participate in daily activities that require for example physical strains. This—sometimes unrecognized or unnecessary—protective behavior and attitude can be considered as overprotection. For more information on overprotection, please refer to chapter 2.

There are two main reasons why the researcher saw overprotection as an issue that needs to be prevented. First, overprotection may lead to negative consequences on the psychosocial and physiological development of children. Second, overprotection prevalence is expected to rise according to the advance medical techniques and a higher CHD survival rate.

Child developmental issue

Children learn through making mistakes, this is no different for children with CHD (CCHD). Children need to experience moderate risk and responsibility to grow and develop their skills. However, overprotection by caregivers deprives children's opportunity to explore the world. Overprotection hinders children's healthy development, contributes to emotional unstable, and even results in distressed transitions to adulthood (Ungar, 2009).

Clinical proof exists that overprotected children often build a distorted perception of the world, "perceiving the world around them as dangerous, failing to assess risks appropriately" (Ungar, 2009). Besides, these children are prone to develop exaggerated separation anxiety, aggressive behavior (Chambers et al., 2011), dysthymia, and anxiety disorder (Parker, 1983). Specifically, overprotected children may react to parents' fears by "either assuming the 'sick role' or by rebelling with risk-taking behaviors" (Chambers et al., 2011). The low self-expectation of these children or a tension relation within the family might be the outcomes. Among them,

the tension parent-child relation also accelerates the negative influences on children's development, as John Bowlby (1952), the author of Maternal Care and Mental Health, emphasized the importance of parent-child relationships by demonstrating "a loving, stable parental relationship is as critical to the young child's survival and health as food and health care" (WHO, 2004).

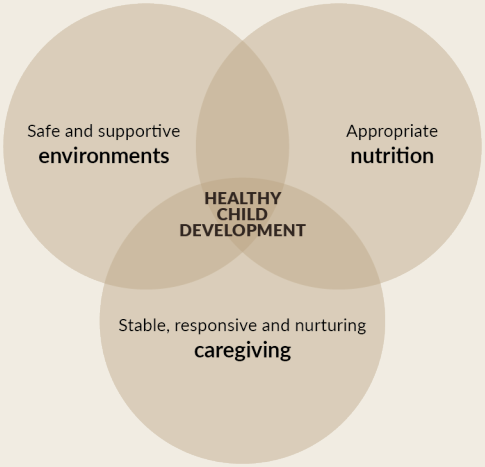
Rising prevalence prediction

Although there is not yet a precise statistic of the prevalence of overprotection because of the lack of large empirical analyses (Duncan & Caughy, 2009), it is expected to increase (Chambers et al., 2011).

Because of the medical advancements, the survival rates for premature infants and children with serious diseases are increasing. According to the American Heart Association, approximately 85% of infants born with cardiovascular anomalies can reach adulthood, and with continued improvement in surgical technique, the survival rate is expected to increase further in the next two decades. However, even if the disease is already cured or palliated, the medical history remains as the trigger to overprotection development. Thus, the increased CHD survival rates indicate the population of parents at risk for overprotection is growing (Thomasgard & Metz, 1995).

Three elements of healthy child development

World Health Organization has proposed three vital elements of healthy child development, which are "stable, responsive, and nurturing caregiving; safe, supportive environments; and appropriate nutrition"("WHO | Child development", 2019). Among these three elements, caregiving, which is referred to offering nourishment, health care, stimulation and emotional support, are believed to be fundamental for healthy child development (Engle & Lhotska, 1999). Parents who overprotect their children might not provide sufficient stimulation for children, thus lead to developmental problems.



1-3.
Project purpose and scope

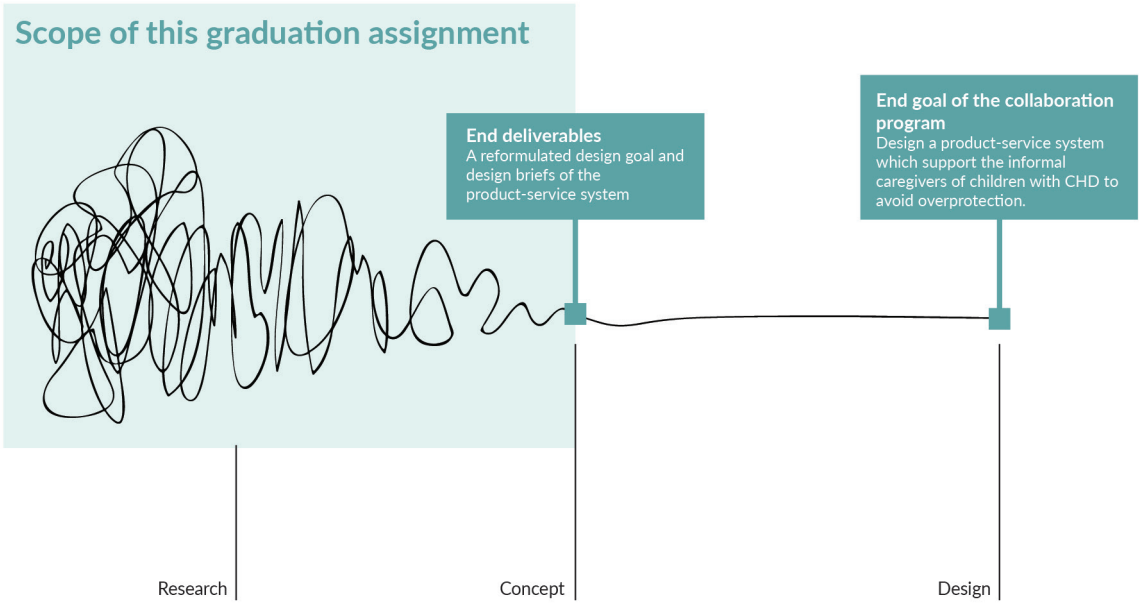


Figure 1. Design Squiggle (Damien Newman) and scope of the graduation assignment

To prevent the unrecognized or unnecessary protection of CCHD, Erasmus MC- Sophia Children's Hospital and Industrial Design Engineering faculty (IDE) of Delft University of Technology set up the collaborative program, aiming to develop a product-service system which supports the informal caregivers of children with CHD to avoid overprotection of these children.

The Design Squiggle, developed by Damien Newman, was chosen to emphasize the fuzziness of the investigation process. The blue shadow in Figure 1 represents the scope of the graduation assignment— the preliminary investigation of the collaborative program.

The goal of the assignment was to create a better understanding of the health-related growing-up experience of CCHD, and overprotective behavior in the context of pediatric cardiology.

Based on the insights, a reformulated design goal of the product-service system and three corresponding design briefs were proposed as the final deliverable.

1-4.
Design approach

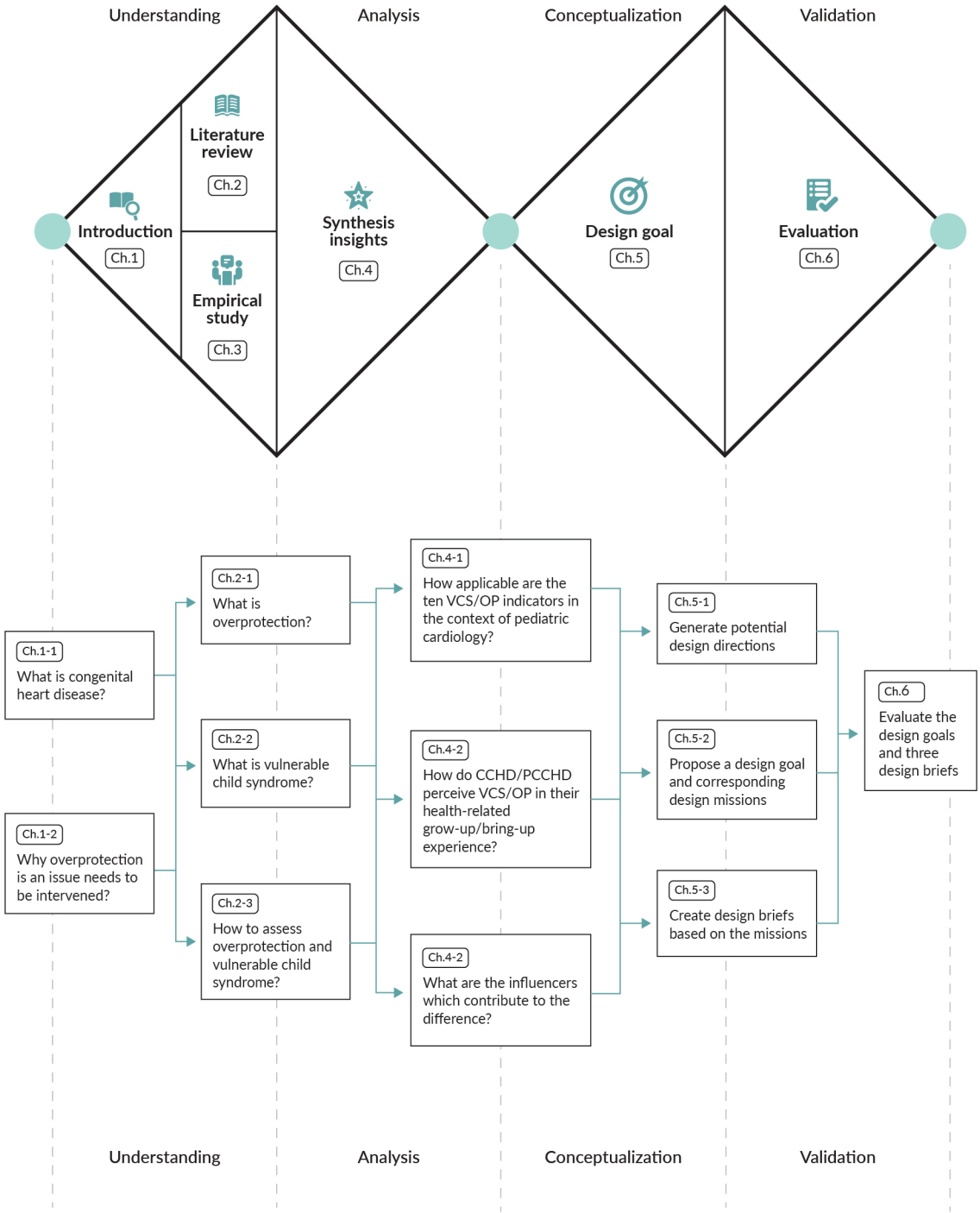


Figure 2. the overall approach of the thesis

The research was structured in four phases: Understanding, Analysis, Conceptualization, and Validation.

Understanding and diving the context is a necessary process to have in-depth knowledge for building up a design solution that can really support users. The literature review and empirical study were two perspectives used to build up a comprehensive knowledge ground.

Chapter 1 provides background knowledge of congenital heart disease (CHD) and overprotection (OP). Besides, two reasons which show the urgency to prevent overprotection in pediatric cardiology are illustrated. The scope and structure of the graduation assignment also are presented in the chapter.

In chapter 2, the researcher digs deeper into the context of overprotection, aiming to answer the following questions: 1) What is overprotection? 2) What is vulnerable child syndrome? and 3) How to assess overprotection and vulnerable child syndrome. Moreover, risk factors, parental challenges and overprotection indicators are addressed.

Besides theoretical knowledge, the voice from potential users also values high. Therefore, empirical research is needed. In chapter 3, the purpose, method, execution, and analysis processes of the empirical study are presented.

Chapter 4 is the synthesization of theoretical and an individual's perspective. Factors proposed in chapter 2 (i.e., risk factors, parental challenge, and indicators) are applied as signals in the narratives that gained from interviewees. By extracting related quotes from interviewees, the significant level of the ten VCS/OP indicators is validated in chapter 4-1. Applying extreme case sampling, the extreme positive and extreme negative cases of overprotection are purposively illustrated in chapter 4-2. By illustrating health journey maps and interaction with people around, the researcher aimed to answer two questions: 1) How do CCHD/PCCHD perceive their health-related grow-up/bring-up experience? 2) Who are the influencers who contribute to the difference?

Key insights are translated into design directions in chapter 5. In chapter 5-1, potential design directions are to be addressed. A design direction is selected and further translated to a design goal in chapter 5-2. The design goal is framed as **"Design a product-service system which facilitates rational discussions within children with congenital heart disease, their parents and medical experts, to achieve a consensus upon diagnosis-specific and personalized boundaries between proper-protection and overprotection."** Three design missions, which work toward the design goal, are proposed. In chapter 5-3, a set of visualized design briefs are generated according to the missions.

To evaluate the design goal and the three design briefs, the chair of the Board of Examiners in Industry Design Engineering faculty, TU Delft are invited to join the evaluation session. The results are shown in chapter 6.

2 LITERATURE REVIEW

In this chapter, knowledge of overprotection that is required for further analysis and conceptualization is presented. The researcher introduces a theoretical understanding of overprotection (OP) and vulnerable child syndrome (VCS). Risk factors and parental challenges are derived. Also, a set of indicators is generated based on the existing overprotection assessment.

2-1. Overprotection

The concept of overprotection was first described by Levy (1931, 1966), who outlined four characteristic dimensions: "1) excessive physical or social contact, 2) prolonged infantilization, 3) active discouragement of independent behavior and social maturity, and 4) either a dominating excess or an overindulgent absence of parental control". It typically happens to "anxious, insecure or domineering parent" (Merriam Webster, 2019), who might claim that the cautious attitude is in the interest of the child's health and welfare. Researchers believe these overprotective parents tend to regulate children's thoughts and behaviors in a pressuring pattern, driven by their own fears (Ong et al., 2011; Soenens & Vansteenkiste, 2010). However, it is understandable that parents might become overprotective when confronted with a life-threatening disease such as CHD. **Designers need to bear in mind the sensitiveness of the issue and avoid pathologizing parental overprotective behaviors.**

After Levy (1931, 1966) proposed the concept of overprotection, research on the topic started to grow. Edwards et al. (2008) proposed overprotection as a parenting style that is **"overly restrictive when it comes to protecting the child from potential harm or risk."** Furthermore, a medical study (Luyckx et al., 2011) investigated the perceived parenting style of 429 adolescents (age 14-18) with CHD. Instead of applying the predominant parental typologies by Baumrind (1978), which used *Demandingness* and *Responsiveness* as two axes to identify parenting styles (for detailed information, please refer to extra reading), Luyckx et al. add a third dimension, *Psychological control*. Psychological control refers to "an intrusive and manipulative form of control expressed through tactics such as guilt induction and contingent love." While demandingness is found to prevent externalizing risky behavior (e.g., alcohol and drug use), psychological control is associated with internalizing symptoms (e.g., depressive symptoms and loneliness). Luyckx et al. defined overprotective parenting as high on demandingness and psychological control and moderate to high on

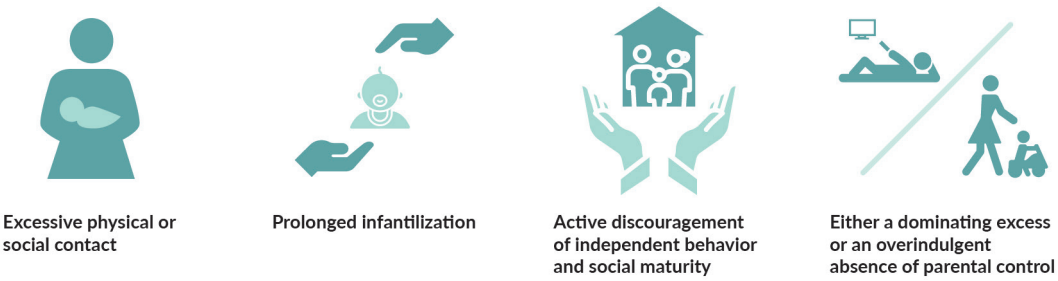


Figure 3. four characteristics of overprotection

responsiveness. The study applied three questionnaires to assess the three dimensions, respectively. Although the questionnaires might need further adjustment for different age ranges of CCHD, the researcher can speculate **parents with high demandingness and psychological control and are moderate to high on responsiveness are prone to overprotection, therefore are the target users of the design intervention for overprotection prevention.**

Besides, an interesting finding is that the overprotective parenting style was identified by both groups of adolescents with CHD and the control adolescents. It is consistent with studies (e.g., Gibson, 1965; McCormick, Shapiro; Starfield, 1982) that **parental tendency of overprotection is based on the emotional reactions of perceiving their child as vulnerable, not on the actual health condition of the child.** Thus, **overprotection could happen irrespective of the objective ability or health condition of the children.** A related concept named *vulnerable child syndrome* is discussed in the following chapter.

Four parenting styles

Numerous studies proposed various dimensions to examined parenting styles. Among all, the most predominant parental typologies are the one proposed by Diana Baumrind (1978) and Maccoby and Martin (1983). They illustrated two dimensions, Demandingness and Responsiveness, to distinguish four parenting styles.

Demandingness refers to "the extent to which parents intentionally foster individuality, self-regulation, and self-assertion by being attuned, supportive, and acquiescent to children's special needs and demands" (Baumrind, 1991). Responsiveness refers to "the claims parents make on children to become integrated into the family whole by their maturity demands, supervision, disciplinary efforts and willingness to confront the child who disobeys" (Baumrind, 1991).

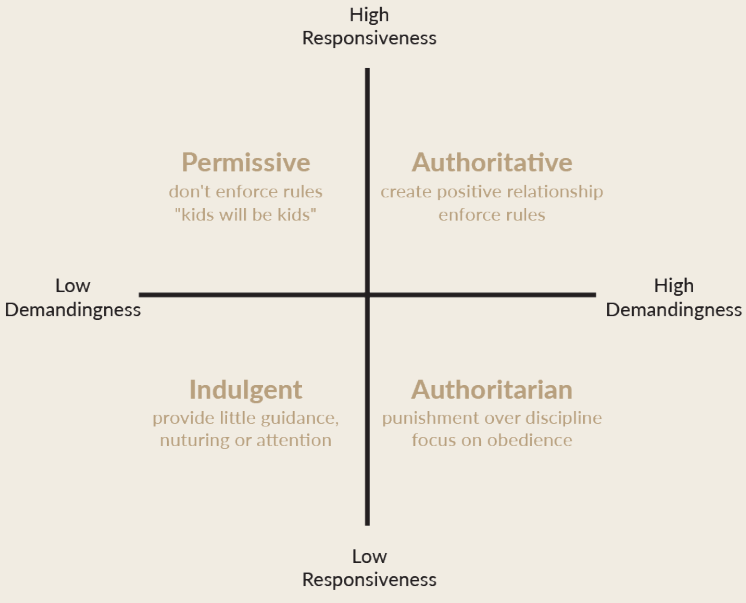
Authoritative parenting, also known as democratic parenting. These parents have high expectations for child achievement, and they support their children to pursue their goals with bidirectional communication and encouragement. Children raised in authoritative families are reported to have a higher level of self-esteem, more competent in school, and are less prone to behavioral problems (Luyckx et al., 2011).

Authoritarian parents make strict rules and orders without really communicating with children, and they expect obedience from children. Children with authoritarian parents have a high risk of developing self-esteem problems and may become aggressive adults.

Permissive parents usually play their role closer to friends of the children rather than parents. They let the child be fully free to act like a child, and do not usually offer guidance for them. Children raised in permissive families are reported to have behavioral problems because their parents barely enforce them to follow rules or build good habits.

Indulgent parenting, also known as uninvolved parenting. These parents spend little time on children. The negligence might owe to busyness or inability. Children with indulgent parents are low in happiness, also exhibit behavior problems.

Among the four parenting styles, authoritative is believed to be the most appropriate because it positively influences the competence and social adeptness of children (Baldwin, 1948; Sears, 1957). Besides, the authoritative parenting style is found related to better treatment adherence, a higher quality of life and fewer psychological symptoms in adolescents with chronic illnesses (Luyckx et al., 2011).



2-2.
Vulnerable child syndrome

Vulnerable child syndrome (VCS) was first identified by Green and Solnit in 1964. VCS refers to the combination of the parental view that their child has a high risk of death, even if the child is objectively healthy. (Forsyth, Horwitz, Leventhal, & Burger, 1996). Precisely, these parents often view their child as susceptible to illness, incapable of being independent, or perform as good as healthy peers. Such a perception is called *perceived child vulnerability*.

Based on observations of children who recovered from a potentially fatal illness, Green and Solnit (1964) found that these families tend to hold the "unfounded belief that the child continued to be at risk for serious illness and was destined to die prematurely" (Thomasgard & Metz, 1997). The belief and attitude may lead to continuing stress and anxiety, deviant family dynamics, unintended medical resource abuse, and even child behavioral problems. A medical study on 196 PCCHD found that the level of perceived child vulnerability among these PCCHD is significantly higher than parents of healthy children, regardless of the severity of the disease (Vrijmoet-Wiersma et al., 2009). In other words, no matter whether the heart disease is mild or severe, PCCHD perceived a higher child vulnerability compared with parents of healthy children. It is consistent with the finding that the parental perception of the illness suffered by their children is far more important than the objective clinical severity (Lawoko, 2007; Wary & Maynard, 2005).

There are many risk factors for the development of VCS, including: first-born child, premature birth, history of loss of a close friend or family member (Green & Solnit, 1964), family health issues, feeding problem during infancy, and history of illness or hospitalization of the child (Chambers, Mahabee-Gittens & Leonard, 2011). Common childhood illnesses or symptoms such as jaundice (Kemper, Forsyth, & McCarthy, 1990), croup (Pearson & Boyce, 2004), or innocent heart murmurs (Bergman & Stamm, 1967) are also reported to trigger VCS development. Among these risk factors, the history of illness and hospitalization usually happens

Illness-specific factors and overprotection

Mullins et al., (2007) have examined the relation between parental overprotection, perceived child vulnerability, parenting stress and uncertainty in youth with chronic illness. Children with asthma and type I diabetes were the represent group of youth with chronic illness in the research. One of the results is that parental overprotection is not associated with uncertainty of the chronic illness. However, a contrast argument was proposed by Holmbeck (2002), who proved the correlation between parental overprotection and problems in children with spina bifida. Although the clarification of the discrepancy results does not exist yet, researchers speculated that illness-specific factors might play a role in it.

Figure 4. risk factor and challenges of VCS/OP

in the context of pediatric cardiology. Therefore, it is considered as a risk factor of VCS development for PCCHD.

Challenge

The core characteristics of VCS have been referred to as **the inability of parents to provide age-appropriate boundaries for their children and the rigid belief in the children's vulnerability** (Duncan & Caughy, 2009).

As mentioned earlier, parents of objectively healthy children could struggle to create the appropriate boundaries, not to mention parents of CCHD who are considered more vulnerable. For children with combined and complex diseases such as CHD, the correct boundaries are even harder to define. In addition, illness-specific factors also influence parents' ability to discern boundaries and directly or indirectly trigger VCS or OP development (For detailed reasoning, please refer to extra reading). Consequently, to create a meaningful design intervention to support people avoiding OP and VCS in the context of pediatric cardiology, CHD-specific factors, such as regular routines of CCHD or overprotective behavior of PCCHD, are the essential considerations.

VCS and OP

Notably, although vulnerable child syndrome and overprotection have been mentioned interchangeably in the literature, they are two different clinical phenomena (Thomasgard & Metz, 1997). **Vulnerable child syndrome indicates parents who hold the anxious cognitions that their children are susceptible to illness and injury** (Anthony, Gil & Schanberg, 2003; Forsyth et al.,1996), such cognitions are referred to *perceived child vulnerability*. The distorted belief which does not match the actual vulnerability of the child is the underlying mechanism of overprotection (Wright et al., 1993). **Overprotection refers to the specific behaviors parents engage, which are "overindulgent, oversolicitous, overprotective and overanxious"** (Levy, 1931; Parker, 1981, 1983), meaning that **the behaviors are not corresponding to the objective level of children needs and capacity.** Accordingly, the researcher can summarize **perceived child vulnerability is the core characteristic of vulnerable child syndrome, and overprotection is an externalizing outcome of vulnerable child syndrome.** Nevertheless, considering the strong cause-effect relations of VCS and OP, the researchers will see the two concepts as a whole and refer them as VCS/OP in the following report.

2-3.
VCS/OP indicators evaluation

After the concepts of VCS and OP were identified, many researchers tried to develop a quantifiable method to measure the tendencies of VCS/OP. However, to the researcher's knowledge, there is not yet a predominant validated VCS/OP assessment for people in pediatric cardiology.

Instead of applying an existing assessment, the researcher decided to refine a new set of VCS/OP indicators by extracting applicable assessment items from the existing assessment. Four assessments were selected, as shown in appendix A. Each of the assessments has different directions and scopes (e.g. parents-reported or children-reported; OP to healthy children or OP to physically vulnerable children) and only validated in a relatively small group. Figure 5 illustrates characteristics of each assessment.

	Appendix 1a. Vulnerable Child Scale (Perrin et al., 1989)	Appendix 1b. Parental Overprotectio Measure (Edwards et al., 2008)	Appendix 1c. The Vulneral Child/ Overprotecting Parent Scale (Wright et al.,1993)	Appendix 1d. Parental Bonding Instrument Scale (Parker et al., 1979)
Perspective	parents-reported	mothers-reported	parents-reported	children-reported
Subject group	children in general	children in general	physical vulnerable children	children in general
Identified concept	perceived child vulnerability	overprotection	overprotection	perceived overprotection
Validation	validated on family with preschool-age children	validated on family with children age three to five	"acceptable"	good internal consistency and re-test reliability in a small group

Figure 5. comparisons of the four VCS/OP assessments

Figure 6. ten indicators of VCS/OP

Refined indicators

After reviewing all fifty-three items from the four assessments, thirty-four items were extracted and clustered into ten indicators of VCS/OP, as addressed in appendix B. Figure 6 illustrates the indicators and definitions. Notably, these indicators are generated from non-CHD-specific assessments since there is a lack of validated CHD-specific assessment. Therefore, these indicators are not yet proven to be perfectly applicable to pediatric cardiology. The researcher will further evaluate and illustrate the applicability in chapter 4-1.

2-4.
Summary and conclusion

In this chapter, the researcher reviewed the literature related to overprotection (OP) and vulnerable child syndrome (VCS). Three themes are highlighted, respectively, risk factors, challenges, and indicators. Key insights of each sub-chapter and a conclusion are presented below.

Ch. 2-1

What is overprotection?

Overprotection is the behavior which overly restrictive regarding protecting the child from potential harm or risk (Edwards et al., 2008). In other words, the behavior is not corresponding to the objective level of children's needs and capacity.

Parents who score high on demandingness and psychological control and moderate to high on responsiveness are reported to have a higher tendency to overprotection (Luyckx et al., 2011)

Ch. 2-2

What is vulnerable child syndrome?

Vulnerable child syndrome indicates parents who hold the distorted belief that their child is susceptible to illness. Such a belief is called perceived child vulnerability.

PCCHD reports a significantly higher level of perceived child vulnerability, regardless of the objective clinical severity of heart disease (Vrijmoet-Wiersma et al., 2009).

Ch. 2-1 + Ch. 2-2

VCS/OP

Consider the strong cause-effect relations of VCS and OP; the two concepts will be discussed together as "VCS/OP" in the following report.

Risk factor

History of illness and hospitalization

There are a number of influencers that trigger VCS/OP development. Among all, the history of illness and hospitalization is the risk factor in the context of pediatric cardiology.

Challenge

Create appropriate boundaries

Hold the rigid belief in child vulnerability

Parental inability to creating the appropriate boundaries for children and the rigid belief in child vulnerability are two challenges of VCS/OP (Duncan & Caughy, 2009). The appropriate boundaries for CCHD are more difficult to define than healthy children because the illness-specific factors also play a role regarding boundaries.

Ch. 2-3

How to assess overprotection and vulnerable child syndrome?

To assess the level of VCS/OP, ten indicators are generated from four existing assessments, as shown below.

To assess the level of VCS/OP, ten indicators are generated from four existing assessments, as shown below. Since the lack of CHD-specific assessment, these ten indicators are for children in general. The applicability and significance of each indicator in pediatric cardiology will be further elaborated in chapter 4-1.

CONCLUSION

Although overprotection (OP) and vulnerable child syndrome (VCS) could happen irrespective of the objective health condition of the child, parents of children with congenital heart disease (PCCHD) are reported a higher tendency on VCS/OP. Therefore, the need for a design intervention that supports these parents to avoid VCS/OP is obvious.

A risk factor, two parental challenges, and ten VCS/OP indicators are derived from the literature for the purpose of building up a solid knowledge ground. However, for designers, insights from people are as important as theoretical knowledge. Therefore, these factors will be brought forward for empirical study, and further integrated and synthesized in the later phases of the project.

3 EMPIRICAL RESEARCH IN PEDIATRIC CARDIOLOGY

Besides theoretical knowledge, the voice from potential users also values high. Therefore, empirical research is needed. In this chapter, the researcher elaborates on the purpose, method, execution and analysis processes of the empirical study.

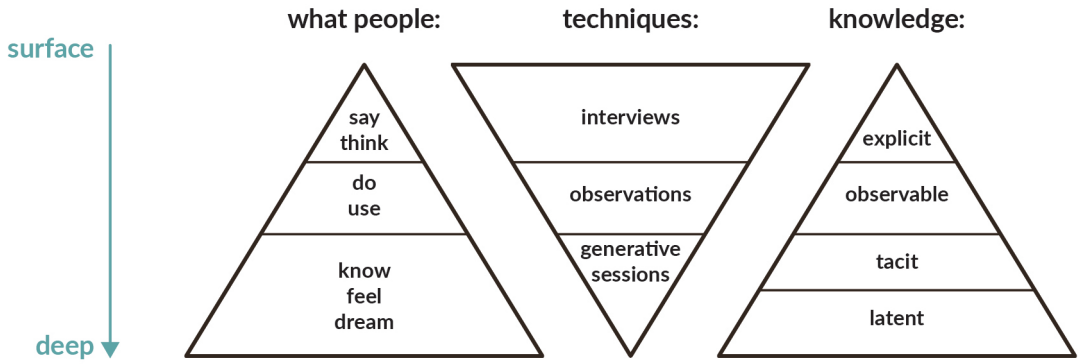


Figure 7. different research techniques access different levels of knowledge (Sleeswijk Visser et al., 2005)

Building a legitimate design solution that supports overprotection prevention in pediatric cardiology requires deep and rooted qualitative insights. The participation of users in the context is highly valuable and essential. (The word "users" here indicates the potential users of the design solution, which include CCHD, PCCHD and related medical experts such as cardiologist, pediatrician, physical therapist and psychologist.) It is necessary to gain insights regarding VCS/OP perception from different users. Health-related grow-up experience of CCHD and bring-up experience of PCCHD are also significant. Collectively, the research could be seen as an ethnographic study carried out for design purposes (Wasson, 2000).

Figure 7 shows the different levels of knowledge, and the techniques to gain the data (Sleeswijk Visser et al., 2005). Interview and observation are widely used techniques in qualitative research, and generative sessions are believed to be more beneficial regarding collecting deep and rooted insights (i.e. tacit and latent). However, considering the hustle and bustle of the healthcare environment, the research should be highly flexible. This means a two-hour generative session with different users involved is not possible in the case. Therefore, a research method that guarantees the in-depth insights and flexibility is applied, called *Learning History Method*.

3-1.
Learning History Method

The learning history method is an ethnographic method that supports designers to understand a complex context, such as design in the healthcare system, by capturing, comparing and combining viewpoints from different users (Kleinsmann, Sarri & Melles, 2018). It is supportive of product/service development, especially fosters the early stage of a complex design project by seeing, exploring, and understanding the details of current practices of users.

The core of the method is "jointly told tales." Jointly told tales to indicate events that are seen from a combined viewpoint of different users in an organization. Precisely, the researcher first interviewed individuals, then integrated the opinions from different individuals to generate a holistic point of view. In this way, latent knowledge can be achieved without generative sessions, but by collecting, comparing and combining viewpoints from different individuals.

Besides experience from different users, the objective knowledge from the existing literature was also incorporated (Kleiner, 2000). The integration of theoretical knowledge and empirical research can also be seen as a form of "jointly told tales." Thus, the present report contains two scopes of "jointly told tales," as shown in figure 8. The big scope is the integration of theoretical and empirical knowledge, and the small scope is the integration of opinions and perspectives from different users.

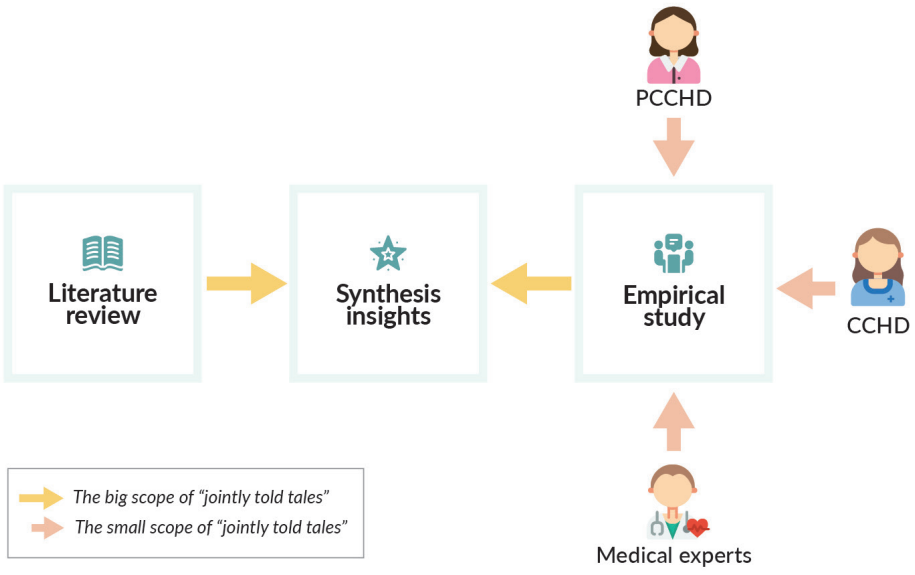


Figure 8. the two scopes of "jointly told tales" in the report

3-2.
Research aim

To the researcher's knowledge and based on the literature review, there is limited research on VCS/OP specifically grounded in pediatric cardiology. However, the discrepancy results from Mullins et al. (2007) and Holmbeck (2002) indicated that illness-specific factors might influence VCS/OP. Thus, a better understanding of VCS/OP in pediatric cardiology is required.

Most of the existing studies on health-related life of CCHD/PCCHD are quantitative research, for example, applying questionnaires to score the perceived quality of life. However, as mentioned, the qualitative data is highly valuable for designers. A design solution could hardly success without the voice of users. Therefore, qualitative insights on users' experiences of health-related life are needed.

To summarize, there are two main goals of empirical research:

1. Gain a deep understanding of VCS/OP in pediatric cardiology
Collecting narratives of VCS/OP, the reasons behind such behaviors, and the emotions toward the behaviors. Referring the narratives to the ten VCS/OP indicators proposed in chapter 2-3. How applicable are the ten indicators? Which indicators have a higher significance in pediatric cardiology?

2. Gain in-depth insights on the perceived health-related life of CCHD/PCCHD
How do CCHD perceive their health-related grow-up experience? How do PCCHD perceive the health-related bring-up experience? How are the interaction and dynamics in the context?

3-3.
Method execution

Following the core idea of the learning history method, three types of interviewees (i.e. CCHD, PCCHD, and medical experts) have participated in the research, and two types of data collection techniques (i.e. interview and attending speech) were applied. Figure 9 illustrates an overview of empirical research.

To recruit interviewees, a promotional poster was made, as shown in Appendix C. It was digitally shared with several patient associations, including Stichting Hartekindand, Harteraad, and TEAMHartvrienden. It was also physically spread in the outpatient clinic in the Cardiac Department, Sophia Children's Hospital.

To ensure flexibility, fluency, and integrity, the interview with CCHD and PCCHD is in semi-structure with a set of interview guides prepared in advance. The interview guide is written in themes. Similar questions are clustered into a theme, with main questions and prob questions. The interviewer can switch between themes according to the natural flow of the conversation. The interview guide is presented in Appendix D.

The research is based in The Netherlands. Considering the topic is relatively sensitive, and people naturally feel more comfortable to express their thoughts and subtle emotion in mother language, a Dutch research assistant was hired to translate the promotional poster and conduct interviews. The interview guide was first written in English, then translate into Dutch after discussing with the researcher about the purpose behind each question. Pilot tests were conducted to ensure the clarity and appropriateness of language framing.

Considering medical experts are more capable to express in English, the interviews with medical experts are therefore conducted in English by the researcher. It is also to speed out the whole research process.

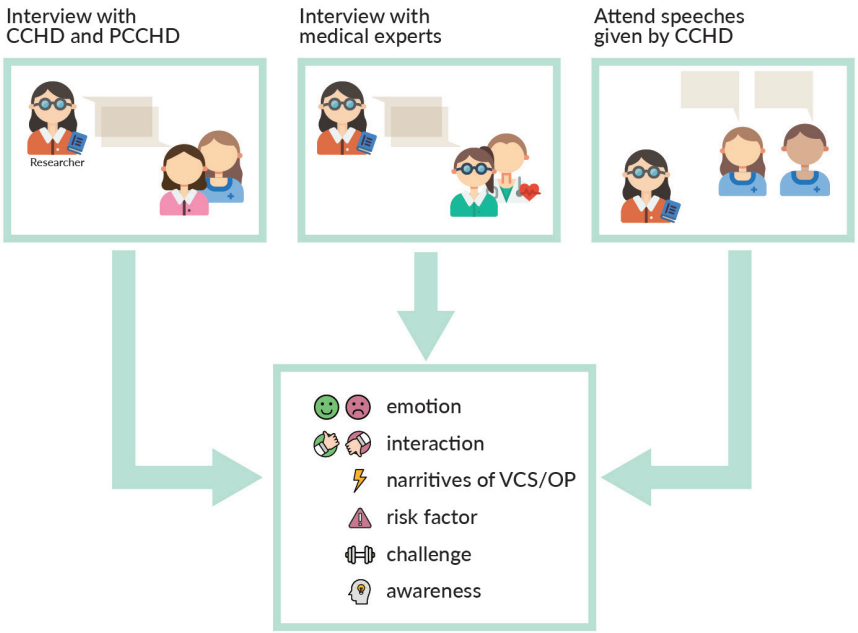


Figure 9. overview of the empirical research

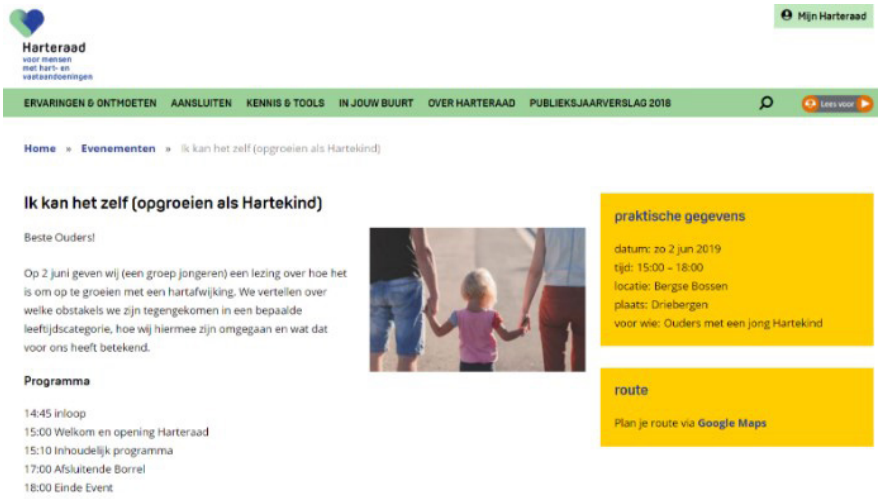


Figure 10. the webpage of sharing event

The sharing event, "I can do it myself- grow up as a Hartekind" hosted by Harteraad, was attended. Five adolescents with CHD gave speeches on their grow-up experience, the obstacles they encountered, and the way they dealt with these obstacles. Figure 10 shows the screenshot of the event webpage. All the speeches are audio-recorded with approval. Harteraad also provided speech notes to support the data collection process.

Nr.	Participants	Age	Data collection technique
1	Cardiologist	-	Interview
2	Patient	16	Interview
3	Parent	-	Interview
4	Physiotherapist	-	Interview
5	Patient	19	Interview
6	Parent	-	Interview
7	Psychologist	-	Interview
8	Patient	16	Attend speech
9	Patient	17	Attend speech
10	Patient	20	Attend speech
11	Patient	19	Attend speech
12	Patient	33	Attend speech
13	Patient	41	Interview

Sample criteria

Based on desk research, key players in the context of cong enital heart disease are selected. Here is the list of criteria:

- Patients who are born with congenital heart disease
- Parent of patients with congenital heart disease
- Medical experts- Cardiologist, Physiotherapist and Psychologist

Compared to the immaturity and susceptible nature of young children, adolescents and adults are more capable to express their opinion on perceived overprotection. Therefore, patients with congenital heart disease age under ten are excluded.

A total number of eight interviews were conducted, and five sharing speeches from adolescents with CHD were collected.

3-4.
Data analysis

All the interviews and sharing speeches were audio-recorded first, then transcribed into text in Dutch. Google translation was used to preliminary understand the context, then the researcher and research assistant had meetings to discuss the context and avoid misunderstanding.

Several user journey maps were roughly mapped out to construct the understanding of CCHD's and PCCHD's health-related life. Medical events, emotion status, and interaction with people around are especially highlighted. Besides, from interviews with CCHD and PCCHD, and the five speeches, narratives on overprotective behaviors were collected.

Three types of VCS/OP factors from the literature review were used as determinants when analyzed the data from the empirical study. Extreme case sampling, a purposive sampling technique used in qualitative research, was applied to gain notable insights on failures and successes ("Purposive sampling | Laerd Dissertation", 2019). Therefore, two overprotection cases on the extreme sides, respectively "positive" and "negative", were illustrated. Each case contains patient persona, parent persona, health journey map, and interactive map. Narratives and quotes which correspond to the determinants are highlighted. Besides the items proposed in the literature review, several new items were found under each factor. Specifically, a power which buffers against VCS/OP development is discerned from the positive case, named beneficial trigger.

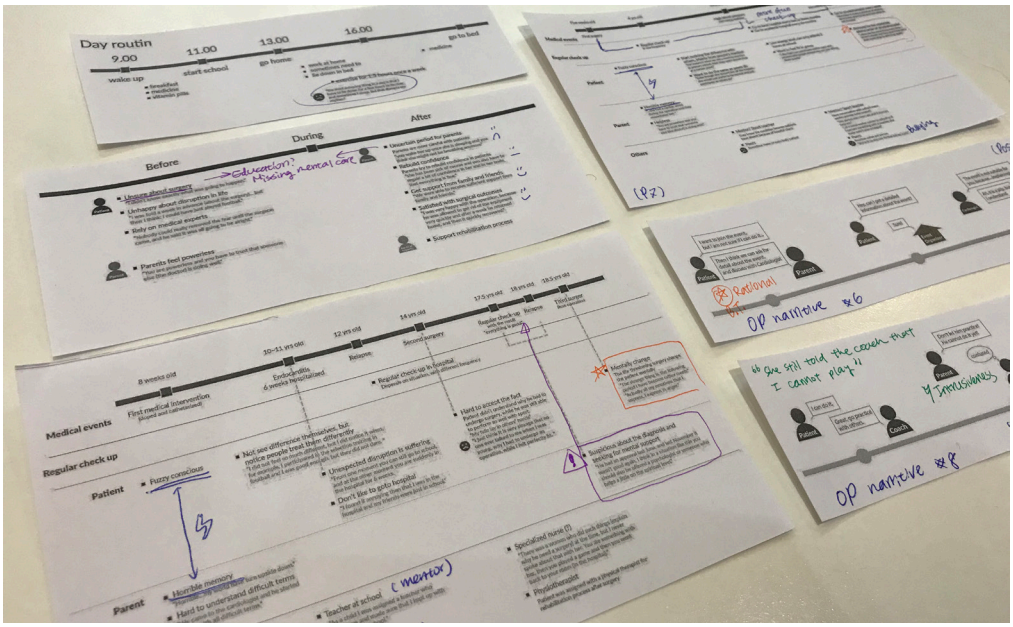


Figure 11. rough sketches of user journey maps

Moreover, as mentioned in chapter 2-3, the ten VCS/OP indicators are not yet validated in the context of pediatric cardiology. Therefore, narratives of overprotection were clustered into each indicator, and the number of times each indicator be mentioned is calculated. During the analysis, the narratives which were no belonged to the existing ten indicators were assigned to new themes. In the end, the significant level of indicators, grounded in the context of pediatric cardiology, is proposed as a reference for prioritized target prevention behavior.

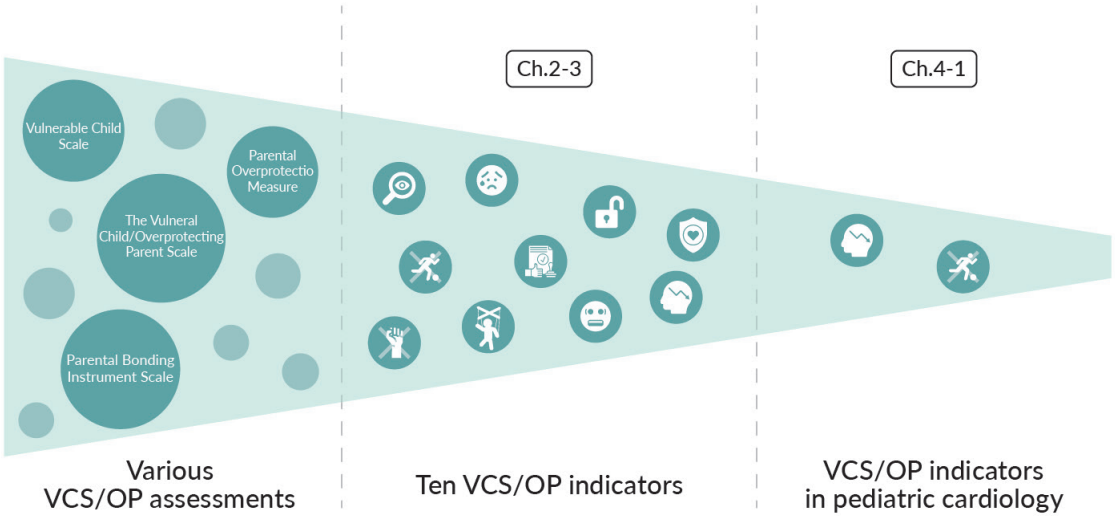


Figure 12. the convergence process of defining VCS/OP indicators

4 SYNTHESIS INSIGHTS

In this chapter, the theoretical knowledge and empirical data are integrated and synthesized. Narratives regarding VCS/OP in pediatric cardiology and the influencers of VCS/OP perception are presented. In addition, two extreme VCS/OP cases are illustrated for the purpose of learning from success and failure. These insights channel to potential design directions and will be further brought to the conceptualization phase.

4-1.
VCS/OP in pediatric cardiology

In chapters 2-3, ten VCS/OP indicators were proposed. To evaluate the applicability in the context of pediatric cardiology, VCS/OP-related quotes the researcher gained in the empirical study were extracted. Each quote was clustered in the corresponding indicators. However, some quotes were fit in more than one indicator. For example, a patient-interviewee mentioned "I feel myself fit and I can play football again, but she (his mom) still calls my trainer and says: 'He cannot play yet.'" In the narrative, the parent not only discouraged exercise but also actively intruded into the patient's autonomy of football practice. Therefore, the quote was clustered in both *Discourage exercise* and *Intrusiveness*. A table showing selected quotes and belonged indicators is presented in appendix E.

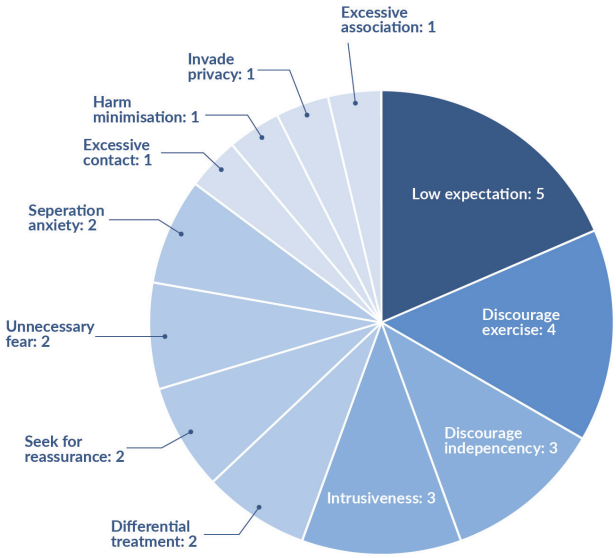


Figure 13. indicators and the number of times mentioned

Interestingly, all ten VCS/OP indicators were mentioned in the empirical study. In addition to these existing indicators, two extra indicators were distinguished, named *Excessive contact* and *Differential treatment*. Excessive contact is consistent with the characteristic of overprotection, "excessive physical or social contact," described by Levy (1931,1966). A representative quote from CCHD is that "They watch me 24/7 and constantly ask how I feel." Besides, the researcher found that interviewees tended to reflect on "whether such behavior also happens on the healthy siblings " when distinguishing proper-protection and overprotection. Therefore, Differential treatment is proposed as a new overprotection indicator. An example is pointed out by a patient-interviewee that "If my brother goes home late, my mom only starts looking for him after 3 hours, but in my case, she would start looking for me after half an hour."

> *My experience is that when you ask the child 'are there any disability?', most of the time they answer very fast "no, I can do everything I want." When I ask and ask and ask, go a little bit deeper, they tell you they have a wheelchair when they go to Efteling or a zoo.*
>
> *- physiotherapist*

Figure 13 shows the indicators and the number of times mentioned. Among all, *Low expectation* and *Discourage exercise* are the two indicators which were mentioned the most, respectively five and four times. Interesting, Low expectation was especially pointed out by medical experts during the interview.

A physiotherapist mentioned her finding that CCHD and PCCHD tend to accept their limitations. They lower the expectations and see the inability as “normal.” It is these incorrect expectations that hinder them from reaching out for support from medical experts.

Therefore, the researcher could speculate these two indicators have a higher significance in the context of pediatric cardiology and view them as the potential prioritized behaviors which need to be prevented. Moreover, these two indicators could also be the evaluation criteria or key performance indicators for the design intervention in the future. However, due to the limited time of the graduation assignment, the data collected is relatively small. Further evaluation of the prioritized VCS/OP behaviors with a bigger group of interviewees is recommended.

4-2.
Extreme cases study

In the empirical study, ten CCHD and PCCHD were interviewed. According to their opinions regarding VCS/OP, the researcher found that the level of perceived VCS/OP among these interviewees are naturally scattered in a spectrum. On the two sides of the spectrum are "positive" and "negative." Positive indicates good patient-parent relation without overprotection reported, whereas negative means tension patient-parents relation with overprotection reported.

Applying the idea of extreme case sampling, learning from both "success" and "failure," extreme quotes and narratives are extracted and represented the positive and negative cases, respectively. Each case consists of patient persona, parent persona, healthy journey map, interaction map, and interesting quotes. Factors proposed in chapter two (i.e. risk factor and challenge) are applied as determinants to investigate the influencers, which contribute to the difference between the two cases.

Figure 14. the level of perceived VCS/OP are scattered in a spectrum

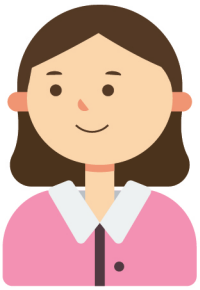
The positive case

Kathy
16 years old
with Patent Ductus Arteriosus

Characteristics
Sensible
Conservative
Cautious

"They don't really say I cannot do things."

Trust
Rational-orientated
Communication and agreement



Irene
42 years old
Kathy's mother

Characteristics
Rational
Supportive
See things in perspective

"We always have a lot of confidence in her own opinion."

5 weeks old — First surgery

6 yrs old — Exercise every day

11.5 yrs old — Hypertension — Low physical strength

15.5 yrs old — Second surgery

Now

Patient

- Fuzzy awareness
  "There was always toys in the waiting room, so I didn't really realize it (the disease)"
- Unequal memory of medical history
- Build up disease awareness from people's reaction
  "I could notice it (the disease) from people around me...when we did a running exercise, they said I should stop at a certain point even I wanted to continue."
- Feel unfortunate
  "I used to exercise almost every day, and I hardly do that anymore. It is unfortunate."
- Get tired easily
- Not feel being understood
  "I sometimes have problems with people around me not understanding it very well. That is difficult."
- Change the school
- Annoyed by the repeating advice/order from physical therapist
  "They say the same thing every time... I know it myself, but they give it the extra push every time."
- Build up sport again with physical therapist

Parent

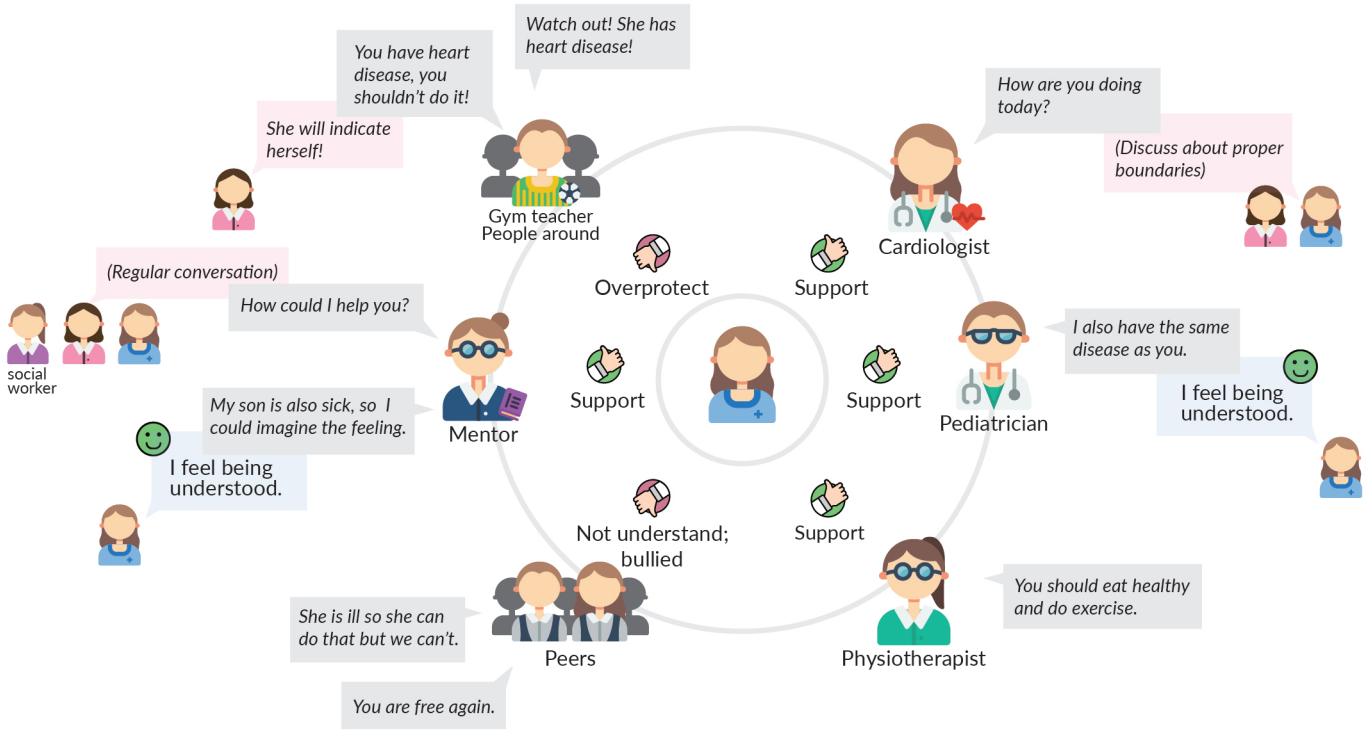
- Confront the life-threatening disease
  "I walked with her in the pram and she turned completely blue...She had a cardiac arrest during operation..."
- Feeling powerless
  "I am powerless and have to trust that someone else (doctor) is doing well."
- Estimate the real reason
  "Sometimes I wonder if she is really sick or if she is pretending to be in puberty, that is sometimes difficult to estimate."
- Get support from family and friends

A child could complain about tiredness because of a bit lazy as well. But that is hard for parents to differentiate that.

This is certainly reported in the literature! It is called ziektewinst in Dutch, and that means that patients exaggerate their symptoms, for example, to receive sickness pay.

Physiotherapist

Cardiologist



Positive situation indicates there are trust, communication, and agreement between patient and parent. They are rational-orientated instead of emotion-orientated. Although risk factors and challenges do occur in their daily life, overprotection is not reported in the situation.

The health journey map shows the medical history and the thoughts of patients and parents in certain moments in life. The congenital heart disease has caused negative emotions for both patient and parent, for example, the feeling of powerless and feeling unfortunate. Besides, starting school life could be a sensitive period for children with CHD. Most of the patient interviewees reported they had a "normal life" when they were young, despite the fact they might have a scar on their chest and regular check-ups in hospital. In other words, the awareness of illness was not formed. Only when they entered primary school, they started realizing that teachers and peers treated them differently. For example, teachers may stop them when they were running. It could be a sensitive period for these children, because the development of self-recognition and the consciousness of illness may influence a lot by people around them. If people keep restricting them from doing certain activities, they might consider those activities as risky, i.e. failing to assess risks appropriately (Ungar, 2009), or they are not able to conduct the activities, i.e. distorted self-capacity and self-expectation.

Ecosystem

Five patients in the research mentioned they have been assigned to a mentor who gives them support on school life. When they have too much absence owing to the health condition, mentors are the ones who report the situation to the attendance officer or compulsory education officer. Notably, all patients in the research pointed out the negative interaction with peers, such as not being understood, being treated differently, isolation and even bullied. Therefore, the interaction with peers is marked as negative, even in the positive case. Three patients in the research eventually changed the school.

Cardiologists, pediatricians, and physiotherapists are the three key medical experts who have been mentioned the most during the research. Cardiologist support on the cardiac issue; pediatrician often plays the role as the center of the medical team; and physiotherapist support patients on physical capability.

All the patient-interviewees mentioned they have experienced overprotection from people around.
For example, people stop the patient from doing exercise or show their fear with an exaggerated reaction even it is only a small accident, such as a fall on the ground. However, it is understandable that people would rather stand on the safe side, especially when they are not familiar with the disease and the potential risk.

Risk factor

Two risk factors of VCS/OP can be discerned in the experience: 1) History of illness and hospitalization and 2) Unequal memory of medical history.

History of illness and hospitalization

It is the risk factor from the literature findings, which is discerned in the experience of all interviewees in the research. Because this project focuses on children with congenital heart disease, history of illness, and hospitalization, these risk factors can be seen as inevitable risk factors in the context of pediatric cardiology.

Unequal memory of medical history

Unequal memory of medical history could trigger unalignment on perceived vulnerability between patients and parents. In other words, the desperate moment happened early in the patient's life can cause a long-lasting fear in the parents' mind, and further lead to excessive concern or even restriction. However, without this memory, the patient might see the concern as unnecessary and even perceived as overprotected. Therefore, the unequal memory of medical history is clustered as a risk factor.

Challenge

A new challenge is reported in the situation, which is **estimating the real reason behind the patient's behavior.** Patients might deny doing certain activities, not because of sickness, but laziness. The behavior has been discussed in medical literature, named "primary gain" or "malingering." It indicates patients produce or exaggerate physical symptoms unconsciously or consciously to achieve certain purposes (Fishbain, 1994; Fishbain et al., 2002). Besides, a physiotherapist also mentioned the PCCHD's challenge to distinguish CCHD's tricks. Therefore, it is a challenge requiring parental ability to see through the potential "trick" from patients and keep the correct demands on them.

> *Sometimes I wonder if she is really sick, or if she is pretending to be in puberty. That is sometimes difficult to estimate.*
>
> *- parent*

> *A child could complain about tiredness because of a bit lazy as well. But that is hard for parents to differentiate that. Is it laziness? Or is it a physical problem?*
>
> *- physiotherapist*

Beneficial trigger

In the positive case, the behaviors and characteristics which buffer against VCS/OP development are found, called beneficial trigger. Four beneficial triggers are especially highlighted, respectively: **1) Rational-oriented, 2) Regular conversation, 3) Transparent discussion toward boundaries, and 4) Trust, understanding, and consensus.** These behaviors were also encouraged in the speeches given by CCHD.

> *Unknown makes misunderstood. Experience shows that I had better tell it, because then people won't look weird to you when you say you can't run a day shift because you can't keep up.*
>
> *- patient*

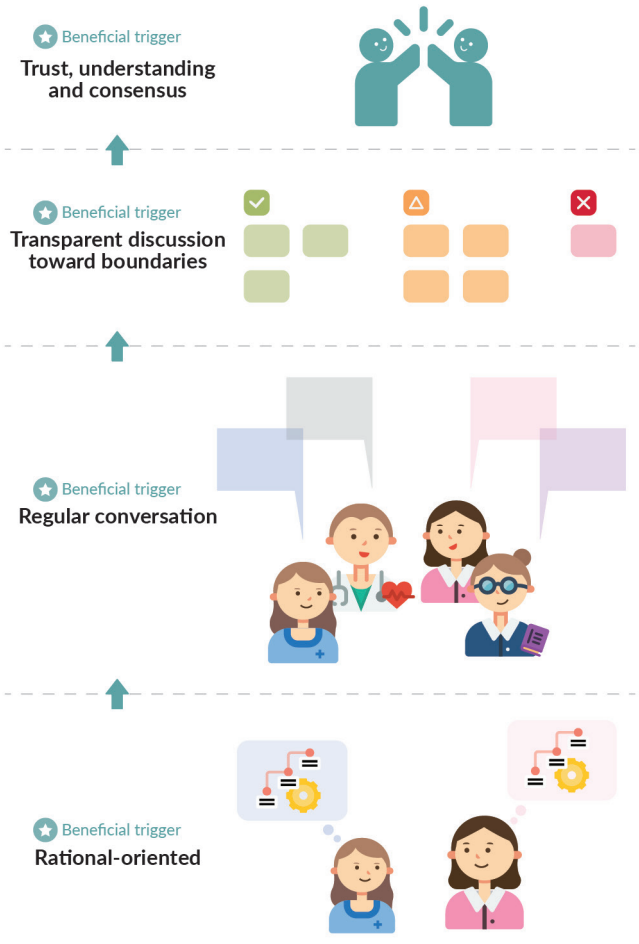


Figure 16. four beneficial triggers

> *It is very important that you communicate everything with your parents.*
>
> *- patient*

> *I still like the agreement! That way I know where I stand and everyone is happy afterward. And I certainly recommend that to other parents. Maybe you don't agree with everything, but start a conversation. Eventually, you will find a way together.*
>
> *- patient*

Being rational helps people see things in perspective and make decisions with thoughtful reasons. It is an essential characteristic that supports people to overcome challenges. For CCHD and PCCHD, staying rational might be more difficult when confronting unexpected or desperate medical events. Therefore, the design intervention should support these people to keep rational or "aware" of their emotions.

Regular conversation is another beneficial trigger for VCS/OP prevention and avoidance. During the conversation, people can discuss their considerations such as obstacles, feelings, needs, wishes, and supports. These topics help people to understand the preferred and proper boundaries between proper protection and overprotection. With regular contacts, people build up trust, understanding, and most important, consensus. The consensus indicates the boundaries are agreed by everyone in the conversation. With a clear consensus, there will not be intrusive behavior (i.e. restriction or suspension) when patients are doing thing they are able to. Also, people know when and how to prepare for support.

Notably, there are unlimited influencers that could also contribute to the avoidance of VCS/OP development, for example, social network, financial status, or the disease or treatment the child has. However, consider the limited time of the project, the influencers who are outside the personality and the ecosystem between family, healthcare organization, and education institution will not be discussed. To be clear, the area with slash in figure 17 is the scope of the beneficial triggers the researcher highlighted above.

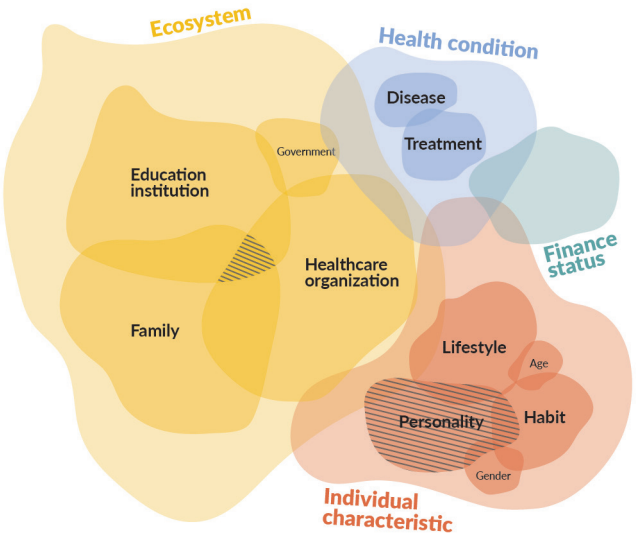


Figure 17. the scopes of beneficial triggers

The negative case

Jason
19 years old
with Aortic valve stenosis

Characteristics
Rebellious
Sporty
Indomitable spirit

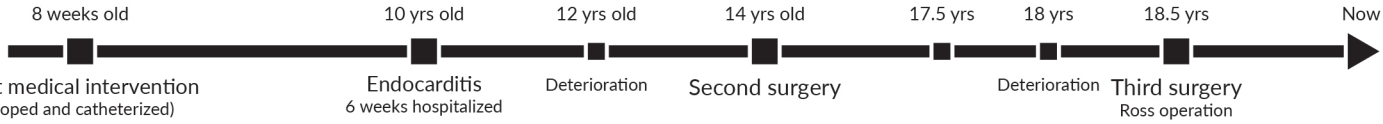
"My mom is trying very hard to protect me."

Conflict
Emotional-orientated
Less communication and agreement

Mandy
40 years old
Jasons's mother

Characteristics
Sentimental
Anxious
Good endurance

"I really needed a psychologist or someone who could support us on spiritual level."



Patient

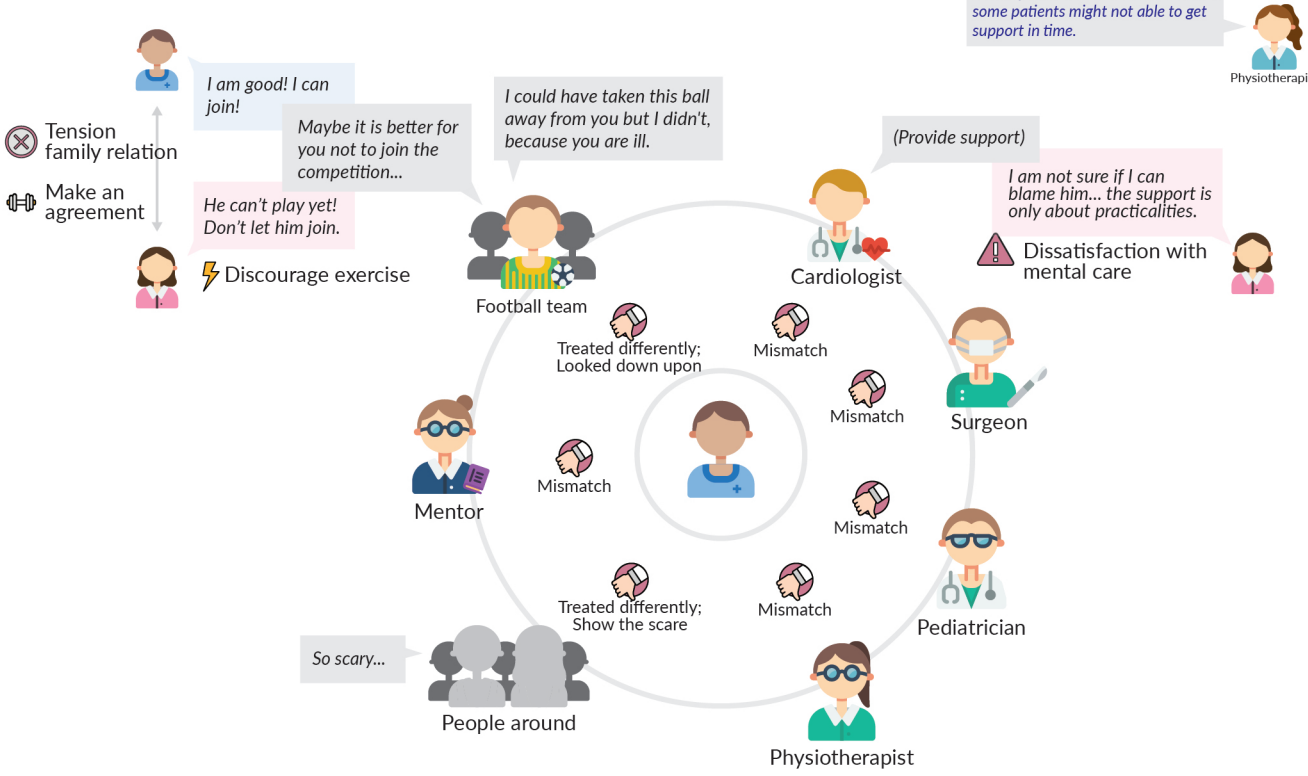
- **Low self-esteem**
  Feels insecured about pectus carinatum
- **Annoyed by life disruption**
  "From one moment you can still go to school, and at the other moment you are suddenly in the hospital for 6 weeks."
- **Powerless**
  "My fate lay in others' hands"
- **Dysthymia** - Emotional isolation
  "I emotionally shut myself off from others. I don't feel I need to talk to others."
- **Aggressive behavior**
  "All my emotions that I express I express in anger."
- **Dissatisfaction with mental care**
  "No one ever talked to me why I had to undergo an operation while I felt perfectly fit. I understood that it was because of my heart valve, but no one was ever assigned to me to explain WHY."
- **Confronting life-threatening disease**
  The Ross operation brings the fear of death

Parent

- **Confront the life-threatening disease**
  "Horrible...my world have turn upside down."
- **Difficult medical jargons**
  "We came to the cardiologist and he started to talk with all difficult terms."
- **Provide appropriate boundaries and sufficient demands**
  "Nobody tell me how to take care of my child. That is my frustration."
- **Seek for reassurance**
  "He was sick for no reason. I had called the doctor whether it had anything to do with the heart... I was at the doctor's office at 8 a.m. because someone had to take a good look at him..."
- **Confront the life-threatening disease**
  "...then it turned out that he got endocarditis and might have died."
- **Provide personalized boundaries**
  "Someone did tell me what he can and cannot do, but that was all very theoretical. He showed different behavior than other children, but I never really had any help with this."
- **Dissatisfaction with mental care**
  "You still live a bit from check-up to check-up. Last June he was healthy, and in November he wasn't good again... I think in this situation you should also be offered a psychologist or someone who helps a little on the spiritual level."

We psychologists cannot initiate consultations with patients. A referral is always needed and it takes time. So some patients might not able to get support in time.

Physiotherapist



The negative case illustrates a tension relation between patient and parent. Conflict often happens, and there are less communication and agreement. Decisions are very much driven by their emotions instead of rational knowledge. In the case, overprotection is perceived and admitted by both parent and patient. Besides the negative emotions brought by heart disease, negative consequences of overprotection are also found, including a symptom of dysthymia and aggressive behaviors.

Risk factor

Two risk factors are found in the journey: 1) History of illness and hospitalization and 2) Dissatisfaction with mental care.

History of illness and hospitalization

As mentioned in the positive case, history of illness and hospitalization is an inevitable risk factor in the context of pediatric cardiology.

Dissatisfaction with mental care

Dissatisfaction with mental care is the main frustration for both patient and parent in the negative case. For example, although there were medical experts explaining the situation to the patient before surgery, he did not feel calmed and supported by the explanation. The great level of uncertainty remained and influenced his following life. On the other side, the parent explained that the support they received is on the theoretical and practical side, such as a brochure teaching how to take a large pill. Missing mental support for a long time increases the risk of emotional instability and stimulates overprotective behavior.

From a psychologist's point of view, the dissatisfaction might relate to the time-consuming referral process. Psychologists cannot initiate consultations with patients actively. A referral is always needed. Since pediatricians and cardiologists are two positions that have frequent contact with CCHD and PCCHD, the referral process is normally done by them. In other words, the responsibility of discerning patients' potential dilemmas (e.g., mental distress or parental behavior issues) is naturally thought to be part of their job. Undoubtedly, it is a challenge to discern everything perfectly in short consultation times, not to mention it may take longer to communicate with young patients.

The referral process might be a reason that obstructs patients from gaining proper mental support. Luckily, Erasmus Hospital is working on a protocol to optimize the current referral processes. With the protocol, psychologists can have initiative to contact patients.

> *"I just think it is very strange that no one ever talked to me when I was young, why I had to undergo an operation, while I felt perfectly fit."*
>
> *-patient*

Challenge

There are three challenges found in the negative case: 1) Provide diagnosis-specific and personalized boundaries; 2) Make the agreement upon boundaries and 3) Difficult medical jargon.

Provide diagnosis-specific and personalized boundaries

Consistent with the literature findings, the challenge of appropriate boundaries is reported in the situation. Notably, the importance of diagnosis-specific and personalized are especially emphasized by parents. An example is that although the parent did receive advice on boundaries from a medical expert, he or she found the advice too theoretical and did not feel it applicable. Therefore, the idea of "appropriate" is further specified as "diagnosis-specific and personalized."

> *Someone did tell me what he can and cannot do, but that was all very theoretical. He showed different behavior than other children, but I never really had any help with this.*
>
> *-parent*

Make the agreement upon boundaries

A narrative from the negative case shows there is no agreement upon boundaries. The patient saw himself good to join the training, while the parent contacted the coach and discourage the training. The conflict not only causes tension in family relations, makes people confused, but also reveals the challenge of making the agreement toward boundaries.

> *I feel that I am fit and I can play football again, but she still calls my trainer and says: 'He cannot play' yet.*
>
> *-patient*

Difficult medical jargon

The other challenge, which is not found in the previous literature review, is the difficulty in understanding medical jargon. It leads to miscommunication and increases parental stress and frustration and will further influence parenting behavior. Therefore, it is proposed as a VCS/OP challenge.

> *We came to the cardiologist and he started to talk with all difficult terms.*
>
> *-parent*

Summary

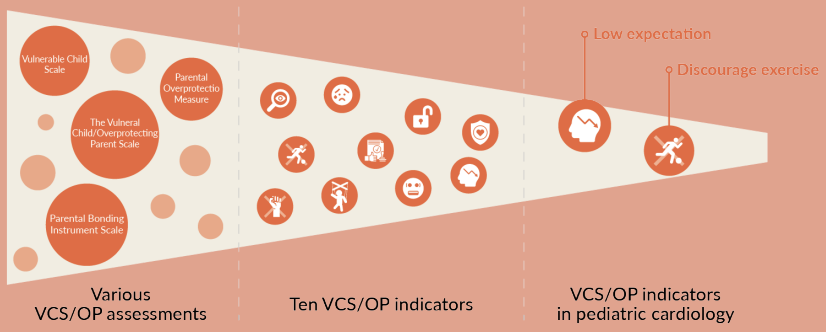
Figure 19. the influencer which distinguishes the two cases is beneficial trigger.

In the positive case, overprotection is not only directly denied by interviewees, but the negative consequences of overprotection (e.g., aggressive behavior, dysthymia, etc.) are not detected in the experience of interviewees either. On the other hand, interviewees who represent the negative case admitted they had encountered overprotection. Negative consequences of overprotection are also found.

Although different types and numbers of risk factors and challenges are found in these two cases, the researcher cannot explain if certain risk factors or challenges have the leading power toward the positive or negative case. The influencer which distinguishes the two cases is beneficial trigger. According to the positive case and the speeches given by CCHD, there are four beneficial triggers highlighted: 1) Rational-oriented, 2) Regular conversation, 3) Transparent discussion toward boundaries, and 4) Trust, understanding and consensus. These behaviors are the determinants that support people to avoid VCS/OP even when facing the risk factors or challenges regarding VCS/OP development. Therefore, it can be viewed as a strong guideline that points out potential directions that the design intervention should work toward.

4-3.
Summary and conclusion

According to narratives gained from interviews and speeches, the applicability of the ten VCS/OP indicators in pediatric cardiology was evaluated. Besides, a positive case and a negative case were derived for the purpose of learning from success and failure. Key insights of each sub-chapter are presented below.



Ch. 4-1

How applicable are the ten VCS/OP indicators in the context of pediatric cardiology?

All ten indicators have been pointed out by interviewees. In addition, two new indicators were generated: Excessive contact and Differential treatment.

Among all, Low expectations and Discourage exercise are the two most mentioned, therefore, have a higher significance than others. Although further evaluation with a larger group is recommended, the researcher could speculate these two indicators as the potential prioritized behaviors that need to be prevented with the design intervention.

Ch. 4-2

How do CCHD/PCCHD perceive VCS/OP in their health-related grow-up/bring-up experience?

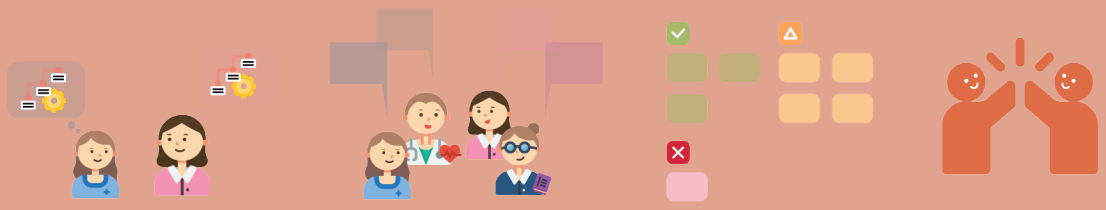
The perception of VCS/OP is scattered in a spectrum, from positive (no perceived VCS/OP) to negative (perceived VCS/OP). Applying the idea of extreme case sampling, extreme quotes and narratives were selected and represented the positive case, and the negative case, respectively. Determinants in these two extreme cases are studied.

Three VCS/OP risk factors and four challenges are identified:

Risk factor
- History of illness and hospitalization — from ch.2-1, the positive case and the negative case
- Unequal memory of medical history — from the positive case
- Dissatisfaction with mental care — from the negative case

Challenge
- Estimate the real reason behind the patient's behavior — from the positive case
- Provide diagnosis-specific and personalized boundaries — from ch.2-1, and specified in the negative case
- Make the agreement upon boundaries — from the negative case
- Difficult medical jargon — from the negative case

Notably, although certain risk factors and challenges were extracted from certain cases, the researcher cannot speculate if certain risk factors or challenges contribute to the positive or negative case.



Ch. 4-2

What are the influencers which contribute to the difference?

Certain behaviors and characteristics only happen in the positive case, and also encouraged by CCHD during the speeches. Therefore, the researcher called these behaviors and characteristics as beneficial trigger. Precisely, beneficial trigger is the power contributes to the difference between the positive and negative cases. It supports people fending off VCS/OP development even when facing risk factors and challenges.

Four beneficial triggers are highlighted: 1) Rational-oriented, 2) Regular conversation, 3) Transparent discussion toward boundaries, and 4) Trust, understanding, and consensus. These beneficial triggers provide potential directions for designers. In other words, the design interventions should guide users toward these beneficial triggers for the purpose of avoiding or preventing VCS/OP development.

CONCLUSION

According to the previous desk research and interviews, the researcher found the complexity and vagueness of defining VCS/OP. Therefore, the researcher evaluated the applicability of the ten VCS/OP indicators for the purpose of scoping down the prioritized targeted behaviors for the design intervention. Moreover, the behaviors could be viewed as evaluation criteria or key performance indicators for the design intervention.

The researcher proposed Low expectations and Discourage exercise as the prioritized targeted behaviors since they had the highest significance among all indicators. However, further evaluation of the results with a bigger user group is recommended.

Furthermore, risk factors, challenges, and beneficial triggers are especially studied in the two extreme cases. A preliminary guideline was proposed as the results to channel the design intervention. Precisely, **to support the users to avoid VCS/OP, the design intervention should prevent the risk factors, support users to overcome the challenges by guiding them toward beneficial triggers.** The conclusion will be further brought to the next chapter, conceptualization.

5 CONCEPTUALISATION

The translation from key insights to tangible design actions is presented and explained in the chapter. It contains a design goal and three missions as the instructions and recommendations for the design intervention.

5-1.
Potential design directions

In the previous chapter, risk factors, challenges, and beneficial triggers were presented and discussed. The initial idea of the design intervention on VCS/OP prevention in pediatric cardiology was generated as "prevent risk factors and support users from overcoming the challenges by guiding them toward beneficial triggers." A translation from the initial idea to several potential design directions is explained in the following paragraphs.

Prevent risk factors

The history of illness and hospitalization, unequal memory of medical history, and dissatisfaction with mental care were found to stimulate VCS/OP in the context of pediatric cardiology.

As a designer, the researcher always tries to solve problems and improve the lives of human beings. However, it is undeniable that the power of design still has limitations. The history of illness and hospitalization of children with heart disease is a fact that is hardly changed by designers, even humans. On the other hand, the unequal memory of medical history between users can be solved if the design intervention helps to 1) align users' perceptions toward medical history, and 2) increase the quality of mental care as a potential solution for CCHD/PCCHD dissatisfaction with mental care.

Overcome the challenges

Estimating the real reason behind children's behavior was pointed out as a parental challenge in the interviews. However, the challenge requires psychological or sociological expertise, such as family therapy. Designers can hardly contribute to the topic without inputs from experts.

Two challenges related to the boundaries were proposed, written as "provide diagnosis-specific and personalized boundaries" and "make the agreement upon boundaries." Accordingly, a design direction can be translated as 3) to provide diagnosis-specific and personalized boundaries, which is agreed by all users.

Difficulty in understanding medical jargon is another challenge mentioned. The difficulty causes stress, frustration, and miscommunication, which indirectly influence parenting behavior. A shared-vocabulary library within medical experts, patients, and parents can improve communication quality. Therefore, a potential design direction can be framed as 4) support users' by building up the shared-vocabulary library.

Guide toward beneficial triggers

The four beneficial triggers are rational-oriented, regular conversation, transparent discussion toward boundaries, and trust, understanding, and consensus. To support CCHD and PCCDH to be rational-oriented, the first step is to raise their awareness toward emotion. Once people are aware of emotion, their thoughts and decisions are less susceptible to emotions. Accordingly, a design direction is framed as 5) raise users' awareness of emotion when making decisions.

Moreover, to have a regular conversation and transparent discussion in a huge organization like the healthcare industry, things need to be arranged beforehand. Therefore, a potential design direction can be generated as **6) arrange and facilitate an efficient information-sharing process within key users.**

Most important, **building trust, understanding, and consensus** are the ultimate goals of the design intervention. It can be seen as the main concept, and designers should bear in mind that all actions should align with it.

To conclude, there are six potential design directions that could prevent VCS/OP on children with congenital heart disease:

1) align users' perceptions toward medical history
2) increase the quality of mental care
3) provide diagnosis-specific and personalized boundaries, which is agreed by all users
4) support users' by building up the shared-vocabulary library
5) raise users' awareness of emotion when making decisions
6) arrange and facilitate an efficient information-sharing process within key users

All these design directions should head toward the ultimate goal, which is **building trust, understanding, and consensus.**

5-2.
Design goal and missions

After having described the potential design directions and the ultimate goal, it is time to further scope down in one field of action. By scoping down, the designer can further channel a design goal. Considering the potential of design and technology, the third, fifth, and sixth design directions are chosen. Accordingly, a design goal is proposed as: **"Design a product-service system which facilitates rational discussions within children with congenital heart disease, their parents and medical experts, to achieve a consensus upon diagnosis-specific and personalized boundaries between proper-protection and overprotection."**

The design goal can be further disassembled into three components presented as follow. From each component, a corresponding design mission is proposed.

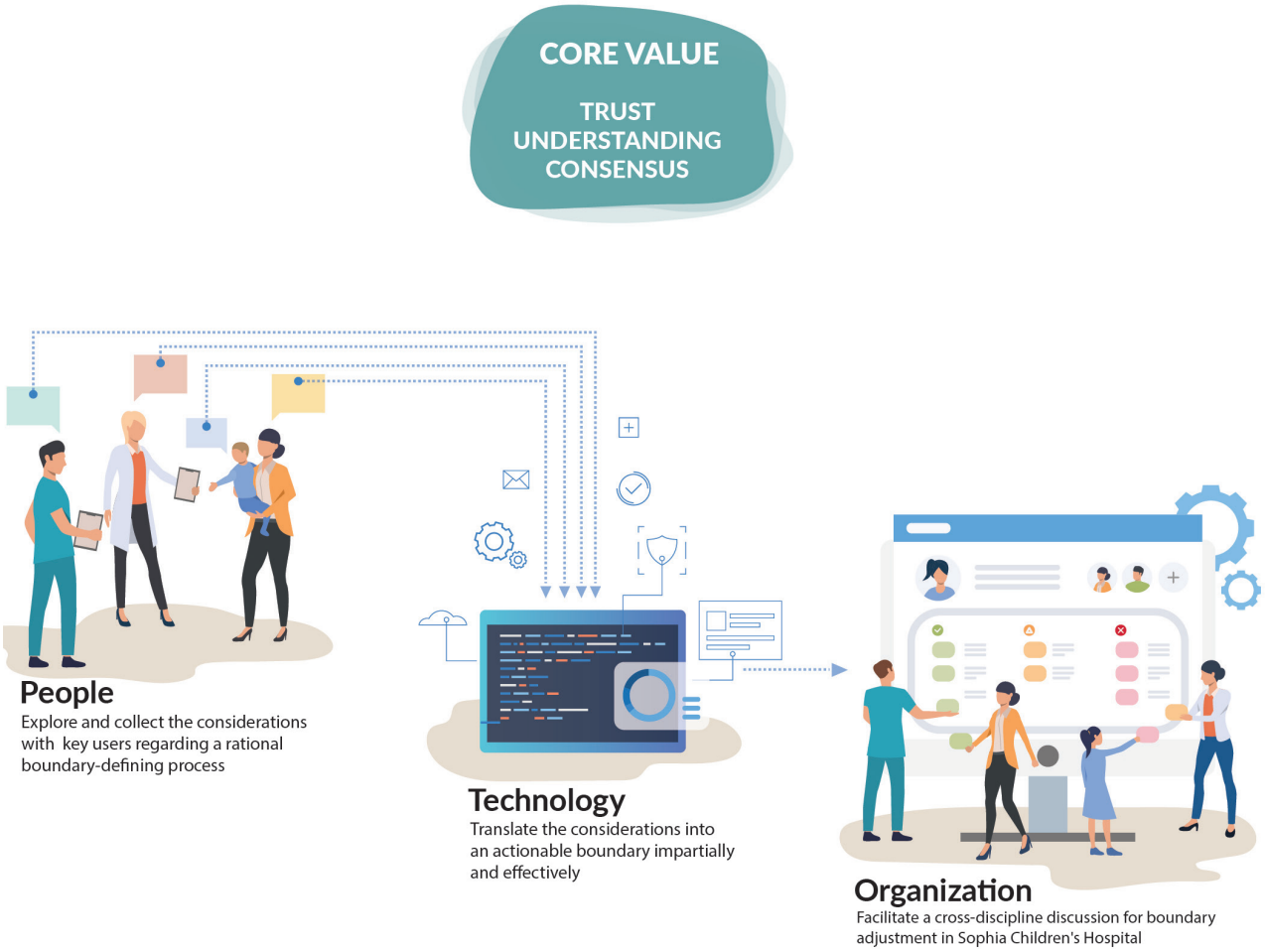


Figure 20. three components of the design goal

People

The proper boundaries should be the outcome after a thoughtful consideration instead of a rush decision driven by emotion. Precisely, several factors need to be taken into account in a rational way. For example, hobby, habit, lifestyle, and upcoming events could be users' considerations regarding the boundaries. A clear list of considerations from all users can also trigger a rational discussion on the proper boundaries. In addition, different people have their own considerations. Designers need to take it into account to achieve personalization. Notably, the prioritize target users are proposed as CCHD, PCCHD, and medical experts in this report; however, it can be further expanded to other players in the context, such as mentors or siblings.

Accordingly, the first step of the product-service system should explore and collect the considerations with users regarding boundary-defining. Hence, a design mission can be framed as:

"Investigate the considerations from each user and propose a rational boundary-defining process."

Technology

The product-service system should facilitate users to achieve the consensus on boundaries. Consensus means that the final outcomes need to be agreed upon by every participant in the decision-making process. Considering every individual has different personalities and their own considerations, the product-service system needs to play an impartial role in the decision-making process. Besides, time is money; effectiveness is always a predominant guideline, especially in the healthcare industry. Therefore, the product-service system should be able to translate the considerations into an actionable boundary impartially and effectively. Accordingly, a design mission is proposed as:

"Design for an algorithm which can calculate users' considerations and further translate into actionable boundaries effectively."

Organization

The boundaries should be diagnosis-specific. It emphasized the importance of professional medical knowledge and consider all the diseases the patient has. This means a cross-departments collaboration might be needed when the patient has more than one disease. However, in such a huge organization with high complexity, even a one-hour meeting with two medical specialists can already cost time and effort to arrange. Moreover, even when people are provided with a guideline on boundaries generated by the algorithm, further discussion and adjustment are still needed. In other words, a cross-discipline information-sharing process with patients, parents, and medical experts (from different departments) need to be arranged. Hence, the product-service system should arrange and facilitate a cross-discipline discussion in Sophia Children's Hospital. In order to arrange such a meeting, the knowledge of the organization structure and workflow is needed. It can also be considered as a preparation for the implementation of the product-service system. Therefore, a corresponding design mission is written as:

"Investigate the organization workflow in Sophia Children's Hospital and propose an implementation plan on the product-service system."

Most important, trust, understanding, and consensus should be the core value behind these design missions. In other words, every action and decision throughout the design process needs to align with the core value.

5-3.
Design brief

According to the design missions proposed in the previous chapter, a set of design briefs are formulated as below, with the purpose of guiding further researchers and designers to identify the overview and objective of the project.

Project overview

According to research, parents of children with congenital heart disease are prone to overprotect their child. Such overprotective behavior not only harms healthy child development but also is expected to be more prevalent in the future. Therefore, Sophia Children's Hospital and Industrial Design Faculty, TU Delft have set a collaboration project to tackle the issue.

The ultimate goal of the collaboration project is framed as below:
"Design a product-service system which facilitates rational discussions within children with congenital heart disease, their parents, and medical experts, to achieve a consensus upon diagnosis-specific and personalized boundaries between proper-protection and overprotection."

According to the goal, three design assignments are proposed as following.

Assignment 1- People

Goal
Investigate the considerations from each user and propose a rational boundary-defining process.

Overview
The assignment starts with the creation of an in-depth understanding of the considerations of each key player (e.g., parents, patients, and medical experts) by interviewing them.
Second, the student will use his/her design skill to determine or quantify the significant level of each consideration regarding the appropriate boundaries between proper-protection and overprotection.
Finally, the student will propose a concept of the rational boundary-defining process.

Targeted student: Design for Interaction/ Strategic Product Design

Design deliverable
1) Lists of considerations of each key player regarding the boundaries-defining process
2) Significance of each consideration
3) A concept of the rational boundary-defining process

Assignment 2- Technology

Goal
Design for an algorithm that can calculate users' considerations and further translate into actionable boundaries effectively.

Overview
The assignment starts with the creation of an in-depth understanding of artificial intelligence and algorithm applied in the medical domain through interviews with experts (e.g., data scientists, AI experts, cardiologist… etc.)
Second, the student will use his/her design skill to propose a concept of a smart product-service system which can translate users' considerations to an actionable guideline on boundaries between proper-protection and overprotection.
Finally, the student will create a prototype of the smart product-service system and conduct an evaluation.

Targeted student: Integrated Product Design

Design deliverable
The prototype of the smart product-service system

Assignment 3- Organization

Goal
Investigate the organization workflow in Sophia Children's Hospital and propose an implementation plan on the product-service system.

Overview
This assignment starts with the creation of an in-depth understanding of the organizational overview in Sophia Children's Hospital, with a focus on cross-departments collaboration.
Second, the student will use his/her design skills to propose an implementation plan of the smart product-service system in Sophia Children's Hospital.
Finally, the student will develop an implementation roadmap as a final deliverable.

Targeted student: Strategic Product Design

Design deliverable
The implementation roadmap of the smart product-service system

6 EVALUATION

The proposed design goal and design briefs are evaluated with an official education organization, the Board of Examiners, of the Industrial Design Engineering faculty, TU Delft. A brief introduction about the Board of Examiners and the evaluation results are presented in the chapter.

6-1.
Evaluation setup

The evaluation session was conducted to gain feedback on the clarity of the wording and feasibility of the design briefs in practice. Since the design briefs are written in the style of master graduation assignment in the faculty of Industrial Design Engineering, TU Delft, feedback from the official education organization, the Board of Examiners, are valued.

The Board of Examiners is the authoritative education organization in charge of determining the study programme in the faculty. They are also responsible to prove the applicability of all graduation assignments. The design brief is a required document of the initial step of a graduation assignment, and the Board of Examiners reviews numerous design briefs every year. Therefore, the opinion of the organization must be highly valuable for evaluation in the present thesis. Consequently, the chair of the Board of Examiners was invited to the evaluation session.

The session was scheduled to take forty minutes. Given the duration, the plan was to evaluate the project overview and the three design assignments in sequence. A print-out poster was provided, as shown in page 50.

6-2.
Evaluation results

In general, reactions to the proposed design goal and design briefs are positive. However, there are also suggestions for improvement, as discussed below.

Elaborative background information

The clarity of the project overview is positive. The chair of the Board of Examiners was able to get the basic background information of the project. However, an elaborative document that provides information more than required could help fellow designers to start the project. Accordingly, the executive summary or the conclusion of the present thesis could be attached as the appendix of the design brief.

Inspiration and stimulation

The chair of the Board of Examiners found the illustrations represent the concept of each assignment nicely and can inspire fellow designers at a certain extent. Besides the used of illustration, the chairman recommended providing related examples of successful design interventions in different fields as stimulation for fellow designers. For example, the design intervention which supports patients with cancer to have a relatively normal life.

The role of the hospital

An important perspective that was not considered by the researcher was proposed—what is the role of Sophia Children's Hospital in each design assignment? Precisely, what kind of support or expertise do designers need from the hospital? if such support is feasible, how to arrange or achieve agreements to ensure the fluency of the assignment? On the other hand, what can people from the hospital expect to gain or to learn from each project? It is essential to discuss with stakeholders and align the expectation from each other before starting such a collaborative programme. Meeting with people from Sophia Children's Hospital is recommended.

7

CONCLUSION

7-1.
Project conclusion

As the initial investigation of a collaborative programme which aims for a product-service system that supports the caregivers of the children with congenital heart disease to avoid overprotection, the project starts with the aim of constructing an in-depth understanding of the life of these children and the overprotective behavior of their caregivers.

To fill in the knowledge gap of overprotection grounded in pediatric cardiology, interviews with people in the context (patients, parents, and medical experts) were conducted in addition to literature research. In addition, an inspiring sharing event was attended. Insights on the grow-up experience with heart disease were collected.

According to the literature research, overprotection (OP) is the overly restrictive behavior regarding protecting the child from potential harm or risk (Edwards et al., 2008), while vulnerable child syndrome (VCS) indicates parents who hold the distorted belief that their child is susceptible to illness. These two concepts were collectively discussed as "VCS/OP" in the thesis. Parental inability to creating the appropriate boundaries for children and the rigid belief in child vulnerability are two challenges of VCS/OP (Duncan & Caughy, 2009).

The history of illness and hospitalization is reported to trigger VCS/OP development. Accordingly, the fact that children with congenital heart disease are found to be overprotected becomes reasonable. Despite the understandability, overprotection still needs to be prevented. The two reasons are 1) it deprived children's opportunity to explore the world and hinders healthy development, 2) it is estimated to become more prevalent in the near future.

Among the twelve VCS/OP indicators. Low expectations and Discourage exercise were mentioned the most during interviews. Therefore, these two indicators are proposed as prioritized behaviors that need to be prevented. Hopefully, in the near future, they can also be the key performance indicators in the evaluation phase of the product-service system.

Four behaviors and characteristics were found to be the main determinants of whether overprotection reported by patients and parents. Such behaviors and characteristics were named as the beneficial trigger in the present report. The four beneficial triggers are 1) Rational-oriented, 2) Regular conversation, 3) Transparent discussion toward boundaries, and 4) Trust, understanding,, and consensus. It preliminarily channels the design directions.

A process of translation and further scoping down the potential design directions were carried out in the conceptualisation phase. A reformulated design goal for the collaborative programme was framed as "Design a product-service system which facilitates rational discussions within children with congenital heart disease, their parents and medical experts, to achieve a consensus upon diagnosis-specific and personalized boundaries between proper-protection and overprotection." To fill in the missing link between the present investigation to the ultimate design goal, three dependent design missions were proposed. Each design mission was further written in a design brief that aimed to provide recommendations for the following designers. A one-pager of the reformulated design goal and three design briefs were delivered as the final result of the graduation thesis.

7-2. Contribution

With comprehensive research in theoretical and empirical perspectives, the present project contributes in three ways.

First, the project contributes to a deep understanding of overprotection and vulnerable child syndrome. It highlights four main factors (i.e., risk factor, challenge, indicator, and beneficial trigger) to express the complicated and subjective issue in a logical manner.

Moreover, the project fills in the knowledge gap between the theoretical definition and empirical narratives of overprotection. Several key determinants were derived first in the existing literature and were continuously identified and generated alongside the empirical study. It ensures the comprehensiveness of the final result.

Last but not least, the project provides guidance and recommendations for following designers by reformulating the ultimate design goal of the collaborative programme and proposing three tangible dependent design briefs. It paves a convincing way toward the well-designed product-service system.

REFERENCE

Ambert, A. (1992). The effect of children on parents. New York: Haworth Press.

American Heart Association. (2019). Retrieved from https://www.heart.org/en

Anthony, K. K., Gil, K. M., & Schanberg, L. E. (2003). Brief report: Parental perceptions of child vulnerability in children with chronic illness. Journal of Pediatric Psychology, 28, 185–190.

Arafa MA, Zaher SR, El-Dowaty AA, Moneeb DE. Quality of life among parents of children with heart disease. Health Qual Life Outcomes. 2008;6:91.

Baldwin, A. (1948). Socialization and the Parent-Child Relationship. Child Development, 19(3), 127-136. doi:10.2307/1125710

Baumrind, D. (1991). The influence of parenting style on adolescent competence and substance use. The Journal of Early Adolescence, 11(1), 56-95.

Becker, W. C. (1964). Consequences of different kinds of parental discipline. Review of child development research, 1(4), 169-208.

Bellinger, D. C., & Newburger, J. W. (2010). Neuropsychological, psychosocial, and quality-of-life outcomes in children and adolescents with congenital heart disease. Progress in Pediatric Cardiology, 29(2), 87-92. Bornstein, M.H. (1989a). Maternal responsiveness: Characteristics and consequences. CA:San Francisco: Jossey-Bass.

Bergman, A., & Stamm, S. J. (1967). The morbidity of cardiac nondisease in school children. The New England Journal of Medicine, 276, 1008–1013.

Bevilacqua F, Palatta S, Mirante N, et al. Birth of a child with congenital heart disease: emotional reactions of mothers and fathers according to time of diagnosis. J Matern Fetal Neonatal Med. 2013;26(12):1249Y1253.

Bruce, E., Lilja, C., & Sundin, K. (2014). Mothers' lived experiences of support when living with young children with congenital heart defects. Journal for specialists in pediatric nursing, 19(1), 54.

Cohen, J., Onunaku, N., Clothier, S., & Poppe, J. (2005). Helping young children succeed: Strategies to promote early childhood social and emotional development. Paper presented at the Research and Policy Report). Washington, DC: National Conference of State Legislatures.

Cowan, J. R., & Ware, S. M. (2015). Genetics and genetic testing in congenital heart disease. Clinics in perinatology, 42(2), 373-393.

Chambers, P. L., Mahabee-Gittens, E. M., & Leonard, A. C. (2011). Vulnerable child syndrome, parental perception of child vulnerability, and emergency department usage. Pediatric emergency care, 27(11), 1009.

Clarke, K., Cooper, P., & Creswell, C. (2013). The Parental Overprotection Scale: Associations with child and parental anxiety. Journal of Affective Disorders, 151(2), 618-624.

Dahan-Oliel, N., Majnemer, A., & Mazer, B. (2011). Quality of life of adolescents and young adults born at high risk. Physical & occupational therapy in pediatrics, 31(4), 362-389.

Dictionary by Merriam-Webster: America's most-trusted online dictionary. (2019). Retrieved from https://www.merriam-webster.com/

Duncan, A. F., & Caughy, M. O. B. (2009). Parenting style and the vulnerable child syndrome. Journal of Child and Adolescent Psychiatric Nursing, 22(4), 228-234.

Edwards, Rapee, Kennedy, 2008. Psychometric properties of a parent-report measure of overprotection in preschool-aged children. Unpublished manuscript.

Eifert GH, Thompson RN, Zvolensky MJ, Edwards K, Frazer NL, Haddad JW, et al. The Cardiac Anxiety Questionnaire: development and preliminary validity. Behav Res Ther. 2000;38:1039–53.

Encyclopedia of Children's Health: Infancy through Adolescence. (2019). Retrieved from http://www.healthofchildren.com/index.html

Engle, P. L., & Lhotska, L. (1999). The Role of Care in Programmatic Actions for Nutrition: Designing Programmes Involving Care. Food and Nutrition Bulletin, 20(1), 121-135. doi:10.1177/156482659902000111

Fishbain, D. A. (1994). Secondary gain concept: Definition problems and its abuse in medical practice. APS Journal, 3(4), 264-273

Fishbain, D. A., Cutler, R. B., Rosomoff, H. L., & Steele-Rosomoff, R. (2002). Does the conscious exaggeration scale detect deception within patients with chronic pain alleged to have secondary gain?. Pain Medicine, 3(1), 39-46.

Forsyth, B. W. C., Horwitz, S. M., Leventhal, J. M., & Burger, A. (1996). The child vulnerability scale: An instrument to measure parental perceptions of child vulnerability. Journal of Pediatric Psychology, 21(1), 89–101.

Gairdner, W.D. (1992). The war against the family. Toronto: Stoddart.

Green, M., & Solnit, A. J. (1964). REACTIONS TO THE THREATENED LOSS OF A CHILD: A VULNERABLE CHILD SYNDROME. Pediatrics, 34(1), 58.

Gregory, M. R. B., Prouhet, P. M., Russell, C. L., & Pfannenstiel, B. R. (2018). Quality of life for parents of children with congenital heart defect: A systematic review. Journal of Cardiovascular Nursing, 33(4), 363-371.

Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., & Kemper, T. (2002). Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: The mediational role of behavioral autonomy. Journal of Consulting & Clinical Psychology, 70, 96–110.

Hoyer J, Eifert GH, Einsle F, Zimmermann K, Krauss S, Knaut M, et al. Heart-focused anxiety before and after cardiac surgery. J Psychosom Res. 2008;64:291–7.

Karsdorp, P. A., Everaerd, W., Kindt, M., & Mulder, B. J. (2006). Psychological and cognitive functioning in children and adolescents with congenital heart disease: a meta-analysis. Journal of pediatric psychology, 32(5), 527-541.

Kemper, K. J., Forsyth, B. W., & McCarthy, P. L. (1990). Persistent perceptions of vulnerability following neonatal jaundice. American Journal of Diseases of Children, 144, 238–241.

Kid Sense Child Development. (2019). Retrieved from https://childdevelopment.com.au/

Kleiner, A. (2000). Car launch: The human side of managing change. Oxford University Press.

Kleinsmann, M., Sarri, T., & Melles, M. (2018). Learning histories as an ethnographic method for designing teamwork in healthcare. CoDesign, 1-19.

Kovacs, A. H., Sears, S. F., & Saidi, A. S. (2005). Biopsychosocial experiences of adults with congenital heart disease: review of the literature. American heart journal, 150(2), 193-201.

Lawoko, S., & Soares, J. J. (2006). Psychosocial morbidity among parents of children with congenital heart disease: a prospective longitudinal study. Heart & Lung, 35(5), 301-314.

Lawoko S. Factors influencing satisfaction and well-being among parents of congenitally malformed hearts children: development of a conceptual model based on the literature review. Scand J Caring Sci 2007; 21: 106–117.

Levy, D.M. (1931). Maternal overprotection and rejection. Archives of Neurologv and Psychiatry, 25, 886889.

Levy, D.M. (1966). Maternal overprotection. New York: Norton.

Linde LM, Rasof B, Dunn OJ. Longitudinal studies of intellectual and behavioral development in children with congenital heart disease. Acta Paediatr Scand. 1970;59:169–76.

Luyckx, K., Goossens, E., Missotten, L., Moons, P., & i-DETACH investigators. (2011). Adolescents with congenital heart disease: The importance of perceived parenting for psychosocial and health outcomes. Journal of Developmental & Behavioral Pediatrics, 32(9), 651-659.

Maccoby, E. E., and Martin, J. A. (1983). Socialization in the context of the family: Parent-child interaction. Handbook of child psychology, 4, 1-101.

Marino, B. S., Lipkin, P. H., Newburger, J. W., Peacock, G., Gerdes, M., Gaynor, J. W., ... & Li, J. (2012).

Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. Circulation, 126(9), 1143-1172.

Markopoulos, P., Read, J. C., MacFarlane, S., & Hoysniemi, J. (2008). Evaluating children's interactive products: principles and practices for interaction designers: Elsevier.

Medical Definition of OVERPROTECTION. (2019). Retrieved from https://www.merriam-webster.com/medical/overprotection

Moller, J. H., Taubert, K. A., Allen, H. D., Clark, E. B., & Lauer, R. M. (1994). Cardiovascular health and disease in children: current status. A Special Writing Group from the Task Force on Children and Youth, American Heart Association. Circulation, 89(2), 923-930.

Mullins, L. L., Wolfe-Christensen, C., Hoff Pai, A. L., Carpentier, M. Y., Gillaspy, S., Cheek, J., & Page, M. (2007). The relationship of parental overprotection, perceived child vulnerability, and parenting stress to uncertainty in youth with chronic illness. Journal of pediatric psychology, 32(8), 973-982.

NHS - Helping you take control of your health and wellbeing. (2019). Retrieved from https://www.nhs.uk/
Ong L, Nolan RP, Irvine J, Kovacs AH. Parental overprotection and heart-focused anxiety in adults with congenital heart disease. Int J Behav Med. 2011;18:260–267.

Parker, G., Tupling, H., and Brown, L.B. (1979) A Parental Bonding Instrument. British Journal of Medical Psychology, 1979, 52, 1-10.

Parker, G. (1981). Parental representations of patients with anxiety neurosis. Acta Psychiatrica Scandinavica, 63, 33–36.

Parker, G. (1983). Parental overprotection: A risk factor in psychosocial development: Grune & Stratton New York.

Pearson, S. R., & Boyce,W. T. (2004). The vulnerable child syndrome. Pediatrics in Review, 25, 345–348.

Perrin, E. C., West, P. D., & Culley, B. S. (1989). Is my child normal yet? Correlates of vulnerability. Pediatrics, 83(3), 355-363.

Piaget, J. (1976). Piaget's theory Piaget and his school (pp. 11-23): Springer.

Popenoe, D. (1988). Disturbing the nest: Family change and decline in modern societies. New York: Aldine de Gruyter.

Purposive sampling | Lærd Dissertation. (2019). Retrieved 5 September 2019, from http://dissertation.laerd.com/purposive-sampling.php#adv-dis

Sears, R. R., Maccoby, E. E., & Levin, H. (1957). Patterns of child rearing.

Singh, B., & Ghimire, P. (2017). Stress and coping among the parents of children with congenital heart disease: A hospital based study. J Health Educ Res Dev, 5(1), 1-4.

Social-Emotional Development Domain - Child Development (CA Dept of Education). (2019). Retrieved from https://www.cde.ca.gov/sp/cd/re/itf09socemodev.asp

Soenens B, Vansteenkiste M. A theoretical upgrade of the concept of parental psychological control: proposing new insights on the basis of self-determination theory. Dev Rev. 2010;30:74 –99.

Thomasgard, M., & Metz, W. P. (1995). The vulnerable child syndrome revisited. Journal of Developmental and Behavioral Pediatrics.

Thomasgard, M., & Metz, W. P. (1997). Parental overprotection and its relation to perceived child vulnerability.

American Journal of Orthopsychiatry, 67(2), 330-335. doi:10.1037/h0080237

Understand Your Risk for Congenital Heart Defects. (2019). Retrieved from https://www.heart.org/en/health-topics/congenital-heart-defects/understand-your-risk-for-congenital-heart-defects

Ungar, M. (2009). Overprotective Parenting: Helping Parents Provide Children the Right Amount of Risk and Responsibility. The American Journal of Family Therapy, 37(3), 258-271. doi:10.1080/01926180802534247

Uzark, K., Jones, K., Slusher, J., Limbers, C. A., Burwinkle, T. M., & Varni, J. W. (2008). Quality of life in children with heart disease as perceived by children and parents. Pediatrics, 121(5), e1060-e1067.

van der Mheen, M., van Beynum, I. M., Dulfer, K., van der Ende, J., van Galen, E., Duvekot, J., ... & Casey, F. A. (2018). The CHIP-Family study to improve the psychosocial wellbeing of young children with congenital heart disease and their families: design of a randomized controlled trial. BMC pediatrics, 18(1), 230.

Warnes, C. A. (2005). The adult with congenital heart disease: born to be bad?. Journal of the American College of Cardiology, 46(1), 1-8.

Wasson, C., (2000). Ethnography in the field of design. Human Organization, 59, No. 4, p. 377-388.
WHO. (2004). The importance of caregiver-child interactions for the survival and healthy development of young children: A review.

WHO | Child development. (2019). Retrieved from https://www.who.int/topics/child_development/en/

World Health Organization. (2019). Retrieved from https://www.who.int/

Wray J, Maynard L. Living with congenital or acquired cardiac disease in childhood: maternal perceptions of the impact on the child and family. Cardiol Young 2005; 15: 133–140.

Wright, L., Mullen, T., West, K., & Wyatt, P. (1993). The VCOP Scale: A measure of overprotection in parents of physically vulnerable children. Journal of clinical psychology, 49(6), 790-798.

APPENDIX

Appendix A.
Four VCS/OP assessment forms

Vulnerable Child Scale

The Vulnerable Child Scale was developed to identify parents' perception of child vulnerability (Perrin, West, Culley, 1989). It consists of sixteen true or false questions, each question is responded with four-scales points. Lower scores represent a higher perceived child vulnerability. It has been validated for used in the family with preschool-age children.

1. In general, my child seems less healthy than other children of the same age.
2. I often think about calling the doctor about my child.
3. When there is something going around, my child usually catches it.
4. My child seems to have more accidents and injuries then other children.
5. My child usually has a healthy appetite.
6. Sometimes I get concerned that my child doesn't look as healthy as he/she should.
7. My child usually gets stomach pains or other sorts of pains.
8. I often have to keep my child indoors or because of health reasons.
9. My child seems to have as much energy as other children of the same age.
10. My child gets more colds than other children of the same age.
11. I get concerned about circles under my child's eyes.
12. I often check on my child at night to make sure he/she is ok.
13. I sometimes worry that my child will die.
14. I feel anxious about leaving my child with a babysitter or at day care.
15. I am sometimes unsure about my ability to care for my child as well as I should.
16. I feel guilty when I have to punish my child.

Parental Overprotection Measure

The Parental Overprotection Measure was established by Edwards et al. (2008). It is used for assessing mother self-reported overprotective behavior. It consists of nineteen questions with five-scales points, ranging from zero (not at all) to four (very much). Instead of testing general attitudes and beliefs, the questions focus on specific behaviors or situations that restrict children's exposure to perceived threat. It shows good predictive validity in the sample of parents with children age three to five years old.

Although Edwards et al. did not publish the entire Parental Overprotection Measure, a subsequent study
of Clark et al. (2013) still reveals valuable insights for the present project. Building upon Parental Overprotection Measure, Clark et al. (2013) investigated on examining the Parental Overprotection Measure in the use of children with anxiety disorder, aged seven to twelve. To achieve a higher accurateness, two related aspects of overprotection were, respectively Harm minimisation and Intrusiveness. Harm minimisation refers to "going beyond what is required to protect the child's emotional wellbeing". Intrusiveness refers to "behaviors which restrict the child's autonomy". These two terms clearly illustrated two aspects of overprotection, therefore are picked up as indicators.

Partially questions from Parental Overprotection Measure:

1. When playing in the park I keep my child within a close distance of me.
2. I protect my child from criticism.
3. I would not allow my child to go out with family friends if I were not present.
4. I am reluctant for my child to play some sports for fear he/she might get hurt.
5. I protect my child from his/her fears.
6. I shelter my child from life's difficulties.
7. I comfort my child immediately when he/she cries.
8. I try to protect my child from making mistakes.
9. I accompany my child on all outings.

The Vulnerable Child/Overprotecting Parent Scale (VCOPS)

	Extremely true	Moderately true	Slightly true	Slight untrue	Moderately untrue	Extremely untrue
1. I would be concerned if my child's ability to relate to older children and adults were not average for his/her age.	1	2	3	4	5	6
2. I taught my child nursery rhymes and helped him/her learn other things when he/she was quite young.	1	2	3	4	5	6
3. I try to maintain consistency between what I say to my child and what I do, especially as regards discipline.	1	2	3	4	5	6
4. I try to reward my child immediately (for learning or developing) rather than with a promise of some later reward.	1	2	3	4	5	6
5. I think it is important for my child to learn or think for him/herself.	1	2	3	4	5	6
6. I was (or will be) involved with my child in trying to help him learn the alphabet as soon as possible.	1	2	3	4	5	6
7. I have high standards for my child's social behavior.	1	2	3	4	5	6
8. I try to teach my child problem solving skills.	1	2	3	4	5	6
9. I encourage my child to spend time by himself/herself sometimes.	1	2	3	4	5	6
10. I encourage my child to try new things.	1	2	3	4	5	6
11. I encourage my child to express emotion verbally and not to take it out on someone or something else.	1	2	3	4	5	6
12. I praise my child in order to help build his/her self-esteem.	1	2	3	4	5	6
13. I do not encourage physical activity for my child.	1	2	3	4	5	6
14. I let my child choose most of his/her own work and play projects.	1	2	3	4	5	6
15. I allow my child plenty of freedom to express himself.	1	2	3	4	5	6
16. Physical exercise is important for all young children, even those with medical problems.	1	2	3	4	5	6
17. Children need privacy in their personal lives as much as adults do.	1	2	3	4	5	6
18. Parents should make time to work with their children in order to help them learn and develop.	1	2	3	4	5	6
19. I think my child is happier because I have an active interest in his daily routines.	1	2	3	4	5	6
20. My child should be taught to disagree when he/she feels an idea is wrong.	1	2	3	4	5	6
21. If my child feels that rules are unfair, he/she should be allowed to say so.	1	2	3	4	5	6
22. If my child is unhappy, I will also be unhappy.	1	2	3	4	5	6
23. Disagreement is normal in most relationships and my child should not be sheltered from it.	1	2	3	4	5	6
24. I worry about my child participating in activities that may be too exhausting.	1	2	3	4	5	6
25. I encourage my child to perform chores and duties around the home.	1	2	3	4	5	6
26. When my child has a problem, I try to let it be known that I understand and support his/her efforts to correct the problem.	1	2	3	4	5	6
27. It is important for me to use a warm and friendly voice when talking with my child.	1	2	3	4	5	6
28. I am often preoccupied and do not give my child as much attention as I should.	1	2	3	4	5	6

Parental Bonding Instrument Scale

	Very like	Moderately like	Moderately unlike	Very unlike
1. Spoke to me in a warm and friendly voice	☐	☐	☐	☐
2. Did not help me as much as I needed	☐	☐	☐	☐
3. Let me do those things I liked doing	☐	☐	☐	☐
4. Seemed emotionally cold to me	☐	☐	☐	☐
5. Appeared to understand my problems and worries	☐	☐	☐	☐
6. Was affectionate to me	☐	☐	☐	☐
7. Liked me to make my own decisions	☐	☐	☐	☐
8. Did not want me to grow up	☐	☐	☐	☐
9. Tried to control everything I did	☐	☐	☐	☐
10. Invaded my privacy	☐	☐	☐	☐
11. Enjoyed talking things over with me	☐	☐	☐	☐
12. Frequently smiled at me	☐	☐	☐	☐
13. Tended to baby me	☐	☐	☐	☐
14. Did not seem to understand what I needed or wanted	☐	☐	☐	☐
15. Let me decide things for myself	☐	☐	☐	☐
16. Made me feel I wasn't wanted	☐	☐	☐	☐
17. Could make me feel better when I was upset	☐	☐	☐	☐
18. Did not talk with me very much	☐	☐	☐	☐
19. Tried to make me feel dependent on her/him	☐	☐	☐	☐
20. Felt I could not look after myself unless she/he was around	☐	☐	☐	☐
21. Gave me as much freedom as I wanted	☐	☐	☐	☐
22. Let me go out as often as I wanted	☐	☐	☐	☐
23. Was overprotective of me	☐	☐	☐	☐
24. Did not praise me	☐	☐	☐	☐
25. Let me dress in any way I pleased	☐	☐	☐	☐

Appendix B.
Refined VCS/OP indicators

Indicators of VCS/OP	items	Source
Low expectation	When there is something going around, my child usually catches it.	A1.
	My child seems to have more accidents and injuries then other children.	
	In general, my child seems less healthy than other children of the same age.	
	My child usually gets stomach pains or other sorts of pains.	
	I worry about my child participating in activities that may be too exhausting.	A3.
Excessive association	My child usually doesn't have a healthy appetite. (*)	A1.
	Sometimes I get concerned that my child doesn't look as healthy as he/she should.	
	My child seems not to have as much energy as other children of the same age. (*)	
	My child gets more colds than other children of the same age.	
	I get concerned about circles under my child's eyes.	
Intrusiveness	I often have to keep my child indoors or because of health reasons.	A1.
	Did not let me do those things I liked doing	A4.
	Did not like me to make my own decisions	
	Did not let me decide things for myself	
	Did not give me as much freedom as I wanted	
	Did not let me go out as often as I wanted	
	Did not let me dress in any way I pleased	
	Tried to control everything I did	
Harm minimisation	I protect my child from his/her fears.	A2.
	I shelter my child from life's difficulties.	
	I comfort my child immediately when he/she cries.	
	I protect my child from criticism.	
	I try to protect my child from making mistakes.	
Separation anxiety	I feel anxous about leaving my child with a babysitter or at day care.	A1.
	I accompany my child on all outings.	A2.
	When playing in the park I keep my child within a close distance of me.	
Discourage independency	Tried to make me feel dependent on her/him	A4.
	Tended to baby me	
	Did not want me to grow up	
	Felt I could not look after myself unless she/he was around	
Discourage exercise	I do not encourage physical activity for my child.	A3.
Unnecessary fear	I am reluctant for my child to play some sports for fear he/she might get hurt.	A2.
Seek for reassurance	I often think about calling the doctor about my child.	A1.
Invade privacy	Invaded my privacy	A4.

(items with * means the items have been adjust conversely, for example “My child usually has a healthy appetite.” have been adjust to “My child usually doesn’t have a healthy appetite.”)

Appendix C.
Promotional poster

Wij zijn Max van Manen en Yun Jung Tsai, studenten van de TU Delft, en we onderzoeken de leefomgeving van kinderen met een aangeboren hartafwijking.

We zien dat er ruimte is voor verbetering in het leven van kinderen met aangeboren hartaandoeningen en hun ouders. Door middel van technische oplossingen, zien wij kansen op verbetering van bijvoorbeeld het monitoren van het hart, de uitwisseling van gezondheidsdata met de arts en een meer directe communicatie met het ziekenhuis. Misschien zijn er andere opties en oplossingen waar je aan hebt gedacht?

We willen u graag uitnodigen om deel te nemen aan het project, omdat we zonder uw verhaal niet tot de beste oplossing kunnen komen.

CardioLab
Technische Universiteit Delft
Faculteit Industrieel Ontwerpen
M.S.Kleinsmann@tudelft.nl
R.J.H.G.vanHeur@tudelft.nl

Door middel van een gesprek, willen we graag te weten komen wat het betekent voor een kind en zijn/haar omgeving om te leven met een aangeboren hartafwijking.

Wij zijn geïnteresseerd in uw ervaringen: mooie momenten, droevige momenten, uitdagingen en overwinningen en hoe dit te verbeteren valt met behulp van technische oplossingen.

Als jullie je verhaal met ons willen delen, stuur dan een mail naar: G.M.vanManen@student.tudelft.nl. Dan nemen wij zo spoedig mogelijk contact met u op voor een afspraak.

Voor wie?
- Kinderen met een aangeboren hartafwijking in de leeftijd van 10 tot 18 jaar.
- Ouders/verzorgers van deze kinderen.

Wanneer?
In mei of juni. Het gesprek zal ongeveer een uur in beslag nemen.

Waar?
Elke locatie waar u zich comfortabel voelt om met ons te praten. Wij komen gerust naar u toe.

Erasmus MC Universitair Medisch Centrum Rotterdam
TU Delft

Appendix D.
Interview guide

Interview with CHD child

Ice breaker	Awareness of difference	Emotion
Break the ice Ask permission for audio record	Memory about growing up Awareness of difference	Biggest wish Self expectation
- What's your name?	- How do you feel about the way you grow up?	What do you want to say to the 5-year-old you?
- How old are you?	**- Do you see difference about the way you grow up, compare to your sister/brother/friend (healthy peer)?**	What do you want to say to the future you?
- Who are you live together with?	(If they say no difference, no restriction, come back to these topic later) When did you start cycling? Did you have swimming lesson? When? Do you participate "avervida"?	**If you are a 100% healthy person now, what is the first thing you want to do?** Why do you think you cannot do it now?
- I am here because I am doing a research about children with heart disease, and I need your help to know more about this content.		What is the moment you looking forward the most during your day? Why?
- May I audio record the session? It will be very helpful for my research. It will be anonymous, and will only be used in my research.		Prompt: Do you like to go to school? Do your classmates or teachers know about your condition?

Medical condition	Social network
Health history, official diagnosis Feeling about their life Current health condition (whether there is huge difference)	People surround them (in general and in medical context) Close partners
- What types of congenital heart disease do you have?	I heard some other kids said when they feel annoyed by the disease, they talk to people close to them. How about you? What do you do when you feel upset or annoyed? Why? How often?
- How many surgical operation have you gone through?	**Who are the people you feel comfortable to talk about your condition?** **Why?**
- When did you have these operations?	I heard that every patients have a special medical team. **Do you know who is in your medical team?** How often do you meet them? **Who are the people you feel more close to?** **Why?**
- Who was accompanied you at that time?	
- How was the experience?	
- How is your condition now? Will you have other sugery in the future? Fully recovered? corrected? palliated?	

Self-reported severity	Life
Opinion about the disease Subjetive severity	Disease impact on life Life rountine Awareness of protected and restricted
- Let's start with something positive. What are good things about having the disease? And what are bad things about having the disease?	**- 0 to 10, to what extent do you think the disease influence your life?** Why? Which aspects of life?
- 0 to 10, to what extent do you think the severity of your condition is? Why? Compare to whom?	**- What regular routines do you have in life, related to the disease?** Which one you like/dislike the most? Why?
	- I heard other kids talking about being protected, or even restricted because of their health condition. How do you feel about it? What kind of protection/restriction? By whom?

Interview with parent

Ice breaker		Parenting style		Emotion
Break the ice Ask permission for audio record		Parenting Attitude to risk		
- Thank you for waiting. We just had a nice talk.		- What are the people who taking care of the child most of the time?		- What do you want to say to those parents who just noticed that their child has a heart disease?
- Besides the thoughts of the child, I also want to know your experience and opinion about taking care of the child.		**- In your opinion, what is the most important consideration when raising a CHD child?** **How does it differ from raising a healthy child?** **What makes the difference?**		- What the the first thing you want to do if your child is now a 100% healthy kid? Why do you think you cannot do it now?
- May I audio record the session? It will be very helpful for my research. It will be anonymous, and will only be used in my research.		**What do you do when the child is doing things you think might be risky to their health condition?** **What types of activities do you think is risky?** **Why do you think it is risky?**		
Experience & social network (past)		**Attitude toward overprotection**		
Past experience Close partner				
- When did you find out the heart disease?		**- We have heard some other parents talked about the way they protecting their child, and some of them noticed it might become "overprotection". How do you think about the issue?** How will you distinguish appropriate protection and over protection?		
- How did you take care of the child?		**- How do you see the border between "challenging them" and "protecting them"?** prompt: For example, if there is an exercise event, (the child) want to participate because his/her friends also participate, but you think the exercise might be too intense for him/her. What do you do?		
- Who gave you support at that time? **Who taught you tips about taking care of the child?**		- How do you think about advantages of overprotection? How about disadvantages?		
- I can imagine it might be stressful or anxious at the beginning. How did you go through it? **Did you talk to someone who you feel close to?** **How did they support you?**		**- Do you think your child is being overprotected?** (If yes) Who overprotect the child? Why do they overprotect the child? (If no, come back to the topic later) When did your child start cycling? Do you sport together?		
Social network (now)				
Difference with past time				
- How about now? Do you keep in contact with those people(supportive partners in the past) ? Is there new groups/partners who come in and give you support?				

Appendix E.
VCS/OP in pediatric cardiology

Indicators of VCS/OP	quote
5_Low expectation/confidence	I participated in the selection training in football and I was good enough, but they did not dare. (CCHD)
	The boy said: “I could have taken this ball away from you, but I didn't, because you have something with your heart. (CCHD)
	They are not even aware of their limitation and the fact that they have more possibility then they used at the moment. (Medical expert)
	They (parents) maybe do not expect the child functioning like normal. (Medical expert)
	My teachers always said "it's not bad! a 6 is also sufficient and you have a logical explanation" but she didn't get it. (CCHD)
4_Discourage exercise	I feel that I am fit and I can play football again, but she still calls my trainer and says: ‘He cannot play yet.’ (CCHD)
	When we did a running exercise in primary school, then they said I should stop at a certain point, but I felt like I wanted to continue because I good to go on. (CCHD)
	Yes sometimes with exercise, then people who don't know so much say that I have to stop, while you can continue. Especially people who don't know much about it then say: Don't do it. (CCHD)
	I wanted to go into a martial art, but that wasn't allowed while it wasn't actually more dangerous for my heart. (CCHD)
3_Intrusiveness	People sometimes take the emergency brake: "Ho! Wait! I'd better not do that if I were you." (CCHD)
	She still tries to control my life. (CCHD)
	I feel that I am fit and I can play football again, but she still calls my trainer and says: ‘He cannot play yet.’ (CCHD)
3_Discourage independency	If he went on school camp, I would make sure the medication went along. (PCCHD)
	I always stayed with him in the hospital when he asked. (PCCHD)
	She still tries to control my life. (CCHD)
2_Separation anxiety	I always stayed with him in the hospital when he asked. (PCCHD)
	If my brother goes home late, my mom only starts looking for him after 3 hours, but in my case, she would start looking for me after half an hour. (CCHD)
2_Unnecessary fear	One of the girls gave me a push and I fell on the ground, and then other said: “Watch out! She has a heart disease!” (CCHD)
	They think that if they give me a little push that I die or something. (CCHD)
2_Seek for reassurance	They watch you 24/7 and constantly ask how you feel. (CCHD)
	You still have a sick child and then you also go to look more often, for example at night and when he cries. (PCCHD)
2_Differential treatment	If my brother goes home late, my mom only starts looking for him after 3 hours, but in my case, she would start looking for me after half an hour. (CCHD)
	I have to say that he was my worry child. When he had a wound, he immediately needed medication. His brother doesn't need that attention. (PCCHD)
1_Invade privacy	My parents are very involved in my love life, especially my mother. Sometimes too much. (CCHD)
1_Excessive association	There was an ambulance coming near my sport club, then she cycles to the sports club to check if I am still good. (CCHD)
1_Harm minimisation	I have always carried him on my arm for the first 2 years and lifted it as soon as he cried. (PCCHD)
1_Excessive contact	They watch you 24/7 and constantly ask how you feel. (CCHD)