Diagnosis: Congenital Heart Defect
The Psychological Impact On Family and Child.
Interventions and Remedies.

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Abstract

Congenital Heart Disease (Defect), not only impacts the wellbeing of the child, but have negative effects through shock, uncertainty, anxiety and guilt that poses a threat on the psychological state of the parents and family involved. The support and comprehensive information given from the healthcare professionals are imperative to create a guideline for the parents affected in such straits. There are many psychological intervention methods of which the common seems to be peer support groups, in order to accommodate a better transition to cope with their new, life long situation. This paper illustrates a general understanding of Congenital Heart Defect (CHD, and an overview of two promising studies, that support parents to cope, and to enhance their quality of life. A further aspect is the perspective toward life, of those children who have reached adulthood living with Congenital Heart Defect.

Keywords: Congenital heart defect, congenital disease, peer support group, psychological Intervention

Zusammenfassung: Angeborene Krankheiten und Herzdefekte wirken nicht nur gegen das Wohlbefinden des Kindes aus, aber auch durch Schock, Ungewissheit, Angst und Schuldgefühle, die eine bedrohende Auswirkung auf dem Seelenzustand der betroffene Eltern und der Familie darstellen. Die Unterstützung und umfassende Informationen von den Angehörigen des Gesundheitswesens sind zwingend erforderlich, um eine Richtlinie für die betroffenen Eltern zu schaffen. Es gibt viele psychologische Interventionsmethoden, aber am meist ausgeübte, im solchen Fällen, sind Selbsthilfegruppen von Eltern mit ähnliche Herausforderungen, um einen besseren Übergang, mit ihrer neuen lebenslangen Situation zu meistern. In diesem Beitrag wird ein allgemeines Verständnis der angeborenen Herzfehler und ein Überblick über zwei, viel versprechende Studien, die Eltern im Umweg mit solche Situationen im Täglichenleben zu unterstützen, um ihre Lebensqualität zu verbessern. Ein weiterer Aspekt ist die Lebensperspektive der Kinder, die das Erwachsenenalter mit kongenitalem Herzfehler erreicht haben.

Schlüsselwörter: Kongenitaler Herzfehler, angeborene Erkrankung, Selbsthilfegruppe, psychologische Intervention.
**Introduction**

Simply from personal experience as well as through peers and friends, it is generally acknowledged, when a pregnancy is diagnosed, there can be several types of reactions towards this news. The emotional response can reach from joy, excitement or relief, to ambivalence, sorrow or anxiety, and everything in between. This is often dependent if an offspring was expected and desired, or did it come as a surprise or shock. Nevertheless, after coming to terms of having an offspring, the emotional concentration is surrounded by the alteration in personal status, from woman to mother, as well as a man to a father. Therefore, becoming a parent may be perhaps one of life’s most significant transitions. A birth experience, especially for mothers, is a physical, emotional as well as a social transition. For fathers and other family members, birth can be an important social transition. For parents, the diagnosis of a congenital heart defect/disease (CHD) in their newborn child represents another complex transitional experience, superimposed on the expected transition to parenthood (Messias et al., 1995).

In this paper, we will elaborate different types of CHD, the possible etiology, and the repercussions imposed on the psychological state of family’s environment. Despite advancements in the medical and surgical fields, the psychological support for parents who have to face the day-to-day challenges and uncertainties in regard to their child’s survival and limitations, is an imperative factor in acknowledging and coming to terms with. To support such families in distress, much has been achieved. This reaches from comprehensive medical information, to many studies and programs in supporting and finding appropriate remedies such as peer-group counseling and therapies, as well as other measures in order to improve and support the psychological hygiene of the effected parents – where a few we have touched upon in this paper, including a pilot study.

An emphasis is also given to the stories of adults who were diagnosed with CHD in their childhood, and their views and perspectives toward life.

It will be apparent that achieving psychological stability and a subjective approach to a **healthy optimism**, could be a key to overcoming constant anxiety as well as **toning down** the daily distress. This is a crucial support families having children with CHD can obtain from resources offered in order to be able to cope and stabilize the immediate family environment, where the child, feeling acutely the home atmosphere, is the main focus of attention.
Congenital Anomalies

Congenital anomalies are also known as birth defects, congenital disorders or congenital malformations. Congenital anomalies can be defined as structural or functional anomalies (for example, metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth, or sometimes may only be detected later in infancy. In general, congenital is referred to the existence at or before birth (WHO, 2016).

- An estimated 303,000 newborns die within 4 weeks of birth every year, worldwide, due to congenital anomalies.
- The most common, severe congenital anomalies are heart defects, neural tube defects and Down syndrome.
- Congenital anomalies can contribute to long-term disability, which may have significant impacts on individuals, families, health-care systems, and societies.
- Although congenital anomalies may be the result of one or more genetic, infectious, nutritional or environmental factors, it is often difficult to identify the exact causes (WHO, 2016).

The above information from the World Health Organization names the most severe congenital anomalies; it is also notable that the first addressed was Congenital Heart Defects.

Congenital Heart Defect/Disease

Congenital heart disease (CHD), as mentioned initially, is in reality a defect, or abnormality of the heart or the blood vessels near the heart, that a baby is born with. This is why many people use the term “congenital heart defect” to address this abnormality. With the advancements in surgical processes, the majority of children born today with CHD will survive, and with appropriate treatment will be able to lead a normal or near-normal life. There are different types of CHD. Some are mild and may not be diagnosed in infancy. Other types of CHD are severe and will be diagnosed soon after birth. Some will also be diagnosed in prenatal screening (World Heart Federation, 2016).

In the last decade, people undergoing heart surgery for severe or complex CHD in qualified centers in the US and Canada, the percentage of patients who left the hospital alive included 91% of newborns, 97% of infants, and 98% of children or adults (Congenital Heart Public Health Consortium, 2012).
Types of CHD

There are several types of CHD. Here we will take a look at 3 examples of such heart defects:

**Atrial Septal Defect (ASD).**

In this condition, there is a hole between the two upper chambers of the heart—the right and left atria. This causes an abnormal blood flow through the heart. Some children may have no symptoms and appear healthy. However, if the ASD is large, permitting a large amount of blood to pass to the right side, symptoms will be noted.

**Ventricular Septal Defect (VSD)**

In this condition, a hole in the ventricular septum (a dividing wall between the two lower chambers of the heart— the right and left ventricles) occurs. Because of this opening, blood from the left ventricle flows back into the right ventricle, due to higher pressure in the left ventricle. This causes an extra volume of blood to be pumped into the lungs by the right ventricle, which can create congestion in the lungs.

**Tetralogy Of Fallot (TOF)**

This condition is characterized by the following four defects:

1. An abnormal opening, or ventricular septal defect, that allows blood to pass from the right ventricle to the left ventricle without going through the lungs
2. A narrowing (stenosis) at, or just beneath, the pulmonary valve that partially blocks the flow of blood from the right side of the heart to the lungs
3. Thickening and/or enlargement of the right ventricle
4. An "overriding" aorta (the aorta lies directly over the ventricular septal defect)

Tetralogy of Fallot can result in cyanosis (bluish color of the skin and mucous membranes due to lack of oxygen).
Diagnosis: Congenital Heart Defect

Congenital heart problems range from simple to complex. Some heart problems can be watched by the pediatrician and managed with medicines, while others will require surgery, sometimes as soon as in the first few hours after birth. A baby may even “grow out” of some of the simpler heart problems, such as atrial septal defect. This defect may simply close up on their own with growth. Other babies will have a combination of defects and require several operations throughout their lives (Lucile Packard Children's Hospital Stanford, 2016).

It is imperative to differentiate between CHD and acquired heart disease such as; Rheumatic Heart Disease, Kawasaki Disease and so forth, due to the fact that such diseases are not present at birth (World Heart Federation, 2016).

**CHD Etiology**

The medical community and researches are on constant pursuit to finding the cause of CHD. To date there are different theories linking to; genetic disorder, and possible environmental factors, however the vast majority of congenital heart defects do not seem to have a particular known cause. Very frequent, mothers will wonder if something they did during the pregnancy caused the heart problem of their offspring. But in most cases, no specific cause can be found. Some heart problems do occur more often in families, so there may be a genetic link to some heart defects (Lucile Packard Children's Hospital Stanford, 2016). Some patients with CHD have other family members with similar conditions. The familial association is however more common with parents and siblings than with other relatives. Furthermore the types of CHD that could occur among family members may be different, but the majority of persons with CHD have no other family members demonstrating this issue. Nevertheless, it is known Parents with CHD are more likely to have children with CHDs, than those without. A newborn in a family without a close relative with CHD has about a 1% chance of having CHD. The risk, however, increases about three times for a family in which the father, mother or sibling has CHD (Øyen et al., 2009).

Newborn infants with the diagnosis of CHD, regardless of its severity, impose a heavy psychological pressure on their parents. Distress, tension and uncertainty may plague the everyday life of such families - and if not addressed and remedied, can become a danger to the well being of the immediate family members involved. Furthermore, when children with CHD become adults, the journey they have made can be very different than those of healthy individuals, which we will elaborate later in this paper.
Parents Of Children With CHD – A Transition

To become a parent could be one of life’s most significant transitions. For mothers, a birth experience can be a physical as well as emotional and social transition. For fathers and other family members, birth is an important social transition. For parents, the diagnosis of a CHD in a newborn child represents another complex transitional experience, superimposed on the expected transition to parenthood. The incidence of CHD is estimated at one percent of all live births. In general, nowadays with the modern medical knowledge and technology, the mother’s pregnancy, labor, and delivery are uncomplicated, and despite CHD in a newborn child, it can be a vigorous, full-term infant who is initially active and alert (Messias et al., 1995).

The severe cardiac defects are usually identified shortly after birth; however mild defects may not be diagnosed until the individual is an adolescent or adult. Parent’s subjective experience of the diagnosis of CHD in their newborn is an area that had received little scholarly attention in terms of research (Messias et al., 1995). In the 70’s, Gudermuth was one of the first to look into the subjective perception and experience of eight mothers of infants and children with ages from 2 to 21 months, who were diagnose with CHD. Gudermuth noticed that parental concerns and perceptions of their infant did not always coincide with the nurse’s perception and interpretation, despite of it being partially helpful in the eyes of the mothers (Gudermuth, 1975).

I.B Gottesfeld in his research identified the cause of internal turmoil of the parents which children diagnosed with CHD, was due to three symptoms; feeling of loss, guilt and the constant sense of uncertainty. Such predominant feelings influence the perception that are often different from those of doctors and nurses who have to deal with such sensitive cases on a constant basis, from a safer emotional distance (Gottesfeld, 1979).

Impacting Quality of Life

There are many factors that impact a family’s quality of life after a child is diagnosed with a birth defect such as CHD. The intensity of the psychological distress can be directly linked to the severity of the birth defect, i.e. hospital stays and surgeries, furthermore the level of medical intervention can exacerbate the family’s quality of life. Finances, interacting with others, siblings and other children in the family, and marital relationships may be impacted severely (Lemacks et al., 2013).
These issues could continue even after a child has been released to having a *regular* life. Many parents are frequently unable or unwilling to partake in *normative* or *typical* social activities. Often this is due to the child being medically fragile or still dependent on medical assistance. Many parents live with a sense of isolation, where it can cause significant anxiety in social settings and even lead distressed parents to further isolate themselves because of feeling *different* from other parents and families – this may increase their depression or mental health suffering.

Merely the routine activities, for instance, a trip to the local park can be difficult since the physical differences between healthy children and theirs can be emphasized when the children are side-by-side (Lemacks et al., 2013).

The impact can also be sensed with siblings and other children in the family, due to them feeling neglected, that could consequently lead to behavioral issues and/or depression – furthermore increasing the feeling of guilt in the parents for not being able to give more time and attention to their other siblings due to lack of time and energy. Consequently, another emotional burden is created when their other siblings resent the child who has a birth defect (Lemacks et al., 2013).

Ultimately, due to the continuous distress, marital relationships are frequently in jeopardy with parents of children with birth defects. Multiple studies recognize this phenomenon, however one particular study from the *Journal of Family Law* stating simply that “*families with special needs children have higher divorce rates*” (Price, 2011). Parents caring for a child with birth defects seldom have time and energy left for their relationship. Often when it comes to separation, the impact of such experience exacerbates the medical symptoms of the child (Price, 2011).

On the other hand, there are also parents who do their utmost to deal with their internal ordeal, by becoming more self-aware, and practicing their train of thoughts and the meaning they are giving to their experience (Messias et al., 1995). To give a better understanding of how mothers may view this life-changing event. To soothe themselves, they try their best to take a positive approach to their views, even if this can be very challenging. Here are some of their thoughts and views:

“[...] for a while, I was afraid to get attached, because I sort of felt that I might lose him. And what happened? Something happened when he was maybe, three, four months old, five months old, I don’t know exactly. But somebody in the neighborhood had a two year old that drowned, and it was awful, and I thought, “You know, it doesn't matter”. I mean, that's a healthy child who's two years old and you lose it anyway. It doesn't matter if you're healthy or not, this child is there for you. So, and that's sort of how I accepted it; it had to do with acceptance, I think.”
Another mother expressed the importance in focusing her *energy* and confronting the *reality*, recognizing the meaning she is giving to the events, which could influence her behavior positively.

“You have to be able to muster up and go through it and keep focused on it. I don’t want to be ‘Pollyannish’, but to look for the silver lining because you’re not going to make it (CHD) go away. And to look for the positive, to look at the value of life and some of the intrinsic things that are coming because of what you have to go through.”

(Messias et al., 1995)

As mentioned earlier, despite the determination to keep a positive view and attitude toward the life-changing situation that can be overwhelming for the parents after the diagnosis of CHD (or other severe birth defects) in their newborn, the distress and anxiety surrounding their new awareness can be very difficult to tame. Parents themselves have also publicly called attention to the emotional aspects of having an infant diagnosed with CHD (Schrey, 1994). To remedy and find solace in this transition, there are different types of intervention and support available. Emotional support, parent groups, and education were proposed as appropriate interventions. In a study that compared parental stress in three different groups, parents of children with CHD reported higher stress levels than parents of children with cystic fibrosis or parents of apparently healthy children (Goldberg et al., 1990). Other studies have shown that psychological processes, such as responses within families having a child with life threatening illness have a substantial impacts on the psyche of all the individuals involved (Brosig C. M., 2007). Furthermore, in terms of behavioral effects, research increasingly proposes, that the psychological factors i.e. worry, mental health, subjective perceptions of severity, and indicators of family functioning, may be even more essential than illness severity or surgical factors in determining results (Bellinger et al., 2009).

**Emotional and Coping Intervention Supports**

The negative psychological impact mentioned earlier as well as other evidence suggests that mothers and families of children with CHD, are unfortunately at high risk themselves for psychological difficulties, therefore enhancing the potential risk level of their children (Doherty et al., 2009). Thus, the importance of intervention and support is paramount. However, it is also
vital to know which professionals can be of assistance, and what programs target such cases for the families as well as the children to receive the appropriate support, and enhance their quality of life.

**Healthcare Professionals and Practitioners (Psychotherapists, Counselors)**

A vital role can be played by the healthcare professionals, in helping families to cope with the challenges involved with children who have birth defects. Communication of a diagnosis of a CHD (or other birth defect) in a baby or child is certainly very difficult. There are different reactions of parents; some taking it fairly well, but some falling apart completely, and everywhere in between (Brosig et al., 2007). Whenever possible, a diagnosis ought to be communicated in clear and comprehensive, however simple terms, but also with compassion (Lemacks et al., 2013). Healthcare professionals should remember to reiterate what they have told the families over multiple appointments even though it may seem redundant, because parents are often so overwhelmed that they often “recall little from the initial consultation” (Begley et al., 2008). Practitioners should take extra care in educating families on what to expect and how to manage their child’s care. With the initial diagnosis, parents are often unable to take in information that may help them. In taking on the role of facilitating such transitions, practitioners may interpret, assess, intervene, or just be there for the family. A relatively simple strategy is to offer and provide opportunities for parents to tell their stories. Listening is imperative if practitioners are to help parents to process and interpret their own information, that is often confusing and paradoxical, while respecting and acknowledging the parent’s own temporal, cultural, and emotional frameworks (Messias et al., 1995). For Health care providers, who are not psychotherapists or counselors, it is vital to reflect on their own constructions and understanding of normality, furthermore being empathetic, hence to recognize how they themselves would manage uncertainty in relation to the diagnosis of CHD. Recognizing and realizing the shock, ambivalence, and uncertainty that parents may be experiencing, is another supportive measure. Family physicians can also serve as linking agents with the community resources in order to assure families of ready access to services they may need (Lemacks et al., 2013).
Interventions and Psychological Support

There have been many studies and researches done to measure the efficacy of peer support groups, where a few will be mentioned here. In general despite every parental combination being unique due to their individuality, there have been clear signs of similarities in thoughts and behaviors when facing situations and events of such emotional magnitude, which is known to dictate the new uncertain path of their lives. It is when parents feel connected to a strong support system that tend to make it easier to navigate the daily challenges with having a child with CHD (Shilling et al., 2013). A review was done on peer support for children with chronic disabling conditions that looked at nine different studies and seventeen papers (Lemacks, 2013). The qualitative studies reviewed, in addition to some quantitative studies, revealed that peer support had positive impact on psychological health and outcomes, but it was also concluded that more research is needed in this area (Shilling et al., 2013). Nevertheless, the qualitative combination emphasizes important characteristics of peer support that appear to be common across different types of support and medical conditions. These include the benefits of finding a shared social identity, the opportunity to acquire practical information and be encouraged by others, going through a process of personal growth, and furthermore finding the ability to support others. These stages of new encounters and experience of mutual support are an overriding theme, hence and important feature of such peer support could potentially be a form of self-sustainability (Shilling et al. 2013).

Take A Breath (TAB), A Pilot Study

There was a pilot study by a group of researchers in Australia, which was called Adapting Acceptance and Commitment Therapy for Parents of Children With Life-Threatening Illness. They piloted a unique parent-targeted intervention, with the aim of reducing parental distress. The intervention was called Take A Breath (TAB), with focus on parents of children diagnosed with a life-threatening illness (LTI). This intervention was designed to assist parents in order to adapt to their child’s diagnosis, treatment, and recovery through TAB, that was combined with acceptance and commitment therapy (ACT) as well as problem-solving skills training (PSST) approach. Participants were 11 parents of children with a diagnosis of cancer, CHD or who had life-saving cardiac surgery at least 4 months prior. Parents completed questionnaires at pre, post, and 6-month follow-up assessing parent posttraumatic stress symptoms (PTSS), as well as the
emotional impact of the child’s LTI (for example: feelings of uncertainty, guilt, sorrow, and emotional resources), and psychological elements targeted by the intervention (parental psychological flexibility and mindfulness) (Burke et al., 2014).

From the information gathered, parents reported substantial reductions in PTSS and emotional impact from their child’s LTI, along with significant improvements in their parental psychological flexibility and mindfulness. Effect sizes were medium to large, and improvements were maintained at 6-month follow-up (Burke et al., 2014). This pilot research indicates TAB intervention has shown the possibility for preventing or reducing parental distress associated with child LTI. Despite this approach being preliminary, these results suggest that focusing on parent’s subjective perceptions in regard to their child’s LTI, could be an effective approach to reducing parental distress (Burke et al., 2014). The researchers also mention that their results indicate the potential for such an approach to be adopted across diverse child diagnoses in the acute pediatric settings.

The Take A Breath program outline was as follows:

1) • Session one provides an overview of the program, the rationale and learning objectives. Parents participate in activities that assist them to share their personal story surrounding their child’s diagnosis and treatment.
   • Practitioners use metaphors and activities to introduce parents to the purpose of the program, its structure, focus, and approach, including how the TAB program will assist them to ‘hold and move’ in valued directions.
   • Parents are provided with metaphors and take part in activities that provide an overview of the key processes that will be covered in the program: Awareness, Values, and Problem Solving.

2) • Session two provides parents with information, skills and practice exercises designed to increase their Awareness.
   • Parents explore the core acceptance and commitment therapy (ACT) processes of Willingness and Cognitive Diffusion via a mix of short talks by practitioners, large and small group discussions, and individual exercises.
   • Parents are also encouraged to explore the workability of their current coping strategies.

3) • Session three continues to introduce parents to core ACT processes, specifically Self as Context and Value-based living are introduced.
   • Parents are provided with metaphors and participate in activities to assist them to identify their Values and to set goals related to those Values.

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At pre-assessment, the report on the parents showed an elevated levels of posttraumatic stress symptoms and levels of uncertainty relating to their child’s illness that were well above the clinical normative mean, respectively. Parents also reported very high levels of guilt, worry and unresolved sorrow as well as anger. Nevertheless, parent’s emotional resources were within the range of the mean for the norming group. However, on post-assessment, Parent’s scores revealed significant reductions in both posttraumatic stress symptoms and the impact of the illness. Parent’s perceptions of access to emotional resources also improved, and results wither continued to improve, or were maintained at follow-up (Burke et al., 2014).

This pilot study seems very promising, and could have the potential to be of invaluable support for parents of children with life threatening illnesses, of which congenital heart defect is included. Nevertheless, the limitations should also be acknowledged, such as small sample size, reliance on parent report data, and lack of a controlled group. So, could it be possible that without TAB, similar improvements could have been achieved in due time? According to this study, perhaps not, since the average time elapsed was greater than 2 years since the diagnosis for children with cancer, CHD – and greater than 6 months post-surgery for the cardiac group (Burke, et al., 2014). Because this is past the acute phase of adjustment, it seems unlikely that levels of distress would show marked spontaneous improvements without additional psychological support, such as that provided by Take A Breath parent intervention (Burke, et al., 2014).
There were two other studies, called *CHIP-Infant* (McCusker C. G., 2009) and *CHIP-School* (McCusker C. G., 2012), which we will briefly elaborate.

**Congenital Heart Disease Intervention Program (CHIP)**

CHIP-Infant was a controlled intervention trial, targeted at parents of infants recently diagnosed with significant CHD and aimed in encouraging mother-infant transactions through psychological education, parent skills training, and narrative therapy, which showed significant gains for infant mental development, feeding, maternal worry, and anxiety at 6 month follow-up (McCusker C. G., 2009). This study was further adapted to support the family in the transition of the child starting school. Hence, CHIP-School study, interventions were essentially about strengthening parenting skills in relation to both general developmental challenges and those specific to parenting a child with CHD, explaining and challenging unhelpful evaluations and assumptions, and training parents in problem prevention therapy to identify and resolve worries and fears (McCusker et al., 2012).

This was a randomized controlled trial with three annual recruitment periods. Therefore, 90 children aged 4-5 years, with their families randomly assigned to an Intervention or Control group before entering school. Families were randomly assigned to the CHIP–School Intervention group, or treatment as usual (Control group). Interventions occurred in the first 2 months of the child’s first year at school. Further data were collected for all participants at the end of the first year at school. The main hypotheses were that participation in the Intervention group would result in improved adjustment for the child and mother compared with those in the Control group. Primary outcome measures were child behavioral adjustment and maternal mental health. Secondary outcome measures included sick days, days absent from school, school functioning, maternal worry, health status, and impact of the illness on the family (McCusker et al., 2012).

An overview of CHIP-School Intervention looked as follows:

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<th>Day Workshop: A 5-hour group workshop for parent(s) of 9–12 participants occurred for each of the three annual groups. Following an overview of the rationale for the intervention and outline of the day, there were three sections to this:</th>
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<td>1) Problem Prevention therapy</td>
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<td>2) Psychological Education (<em>Psychoeducation</em>)</td>
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<td>3) Parenting Skills</td>
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In addition to the personalized factsheets, families were handed an illustrated program manual, summarizing all aspects of the workshop. Additional resources and information related to the workshop content were included.

(continues on next page) (McCusker et al., 2012)
**A Bicycle Exercise Stress Test**, 1-4 weeks after Parent Workshop: One of the most omnipresent worry of the parents is in regard to the child’s safety in physical activity. The children took part in a specially designed bicycle stress test, with their heart being monitored constantly through ECG.

**An Individual Parental Session**, 1-4 weeks after the Bicycle Exercise.

**Outreach to community services.** A comprehensive information and fact sheets where to get help in case of emergency.

(McCusker et al., 2012)

The information is merely highlighting the steps in the CHIP-school program and the complete description is more detailed and comprehensive.

Results showed there were positive gains found at 10-month follow-up in terms of maternal mental health and perceived personal tensions in the family. These are vital findings, given the importance of maternal adjustment for child outcomes. Furthermore, the children in the Intervention group missed fewer days from school, and had been less often sick than those in the Control group. Together, these are encouraging findings that support merging psychological interventions into the program of care delivered to children with CHD, and arguably chronic illness in general (McCusker et al., 2012). In addition to the positive gains found on formal outcome measures, the program’s acceptability data suggested high levels of parental appreciation of the elements in the program. The vast majority of mothers’ subjective reports were of gains in accumulated knowledge, understanding, and parenting competencies. All elements of the CHIP-School program were taken very positively.

There are however a number of limitations in this study that must be mentioned. There was no control for the non-specific impact of having the additional contact time involved in delivering the specifics of the intervention. Therefore given the encouraging findings, additional resources will be required including independent ratings of treatment reliability for future research trials (McCusker et al., 2012).

“The CHIP studies are innovative in targeting interventions at key developmental transitions. This principle might inform future intervention research, as effects are likely to be enhanced at these critical times of challenge, adjustment and change. Although we included children with other comorbid physical illnesses, we did not include children with neurodevelopmental
syndromes in this arm of the study. These were included, however, in our CHIP–Infant study, and findings therein (McCusker et al., 2009) support generalizability potential. Moreover, the principles of this intervention program would appear to have generalizable potential to other pediatric populations and transitions, such as adolescence and from child to adult services” (McCusker et al., 2012).

**Living with CHD**

There has been much evidence pertaining children with significant CHD who are increasingly at risk for problems with behavioral adjustment and cognitive functioning (Bellinger & Newburger, 2010). Problems in the areas of anxiety, depression, attention, social cognition, and relationships have been noted with some suggestions that difficulties increase with age and remain manifest in young adulthood (McCusker et al., 2012). Studies have also suggested that approximately 20% of children with CHD, that is more than twice that of healthy peers, fall into the clinically significant range on records of psychopathology (Bellinger & Newburger, 2010). Adults with CHD are a growing population since the results of open-heart surgery in children is constantly improving. Consequently, this growing number may be at risk for psychological problems, particularly depression that often demands psychotherapeutic or psychiatric attention. An increased incidence of depression in adults with CHD was first suggested by studies conducted at Harvard medical school (Bromberg et al., 2003). Another single-center study from The Children's Hospital of Philadelphia (CHOP) also discovered that as many as one in five adult patients had PTSD symptoms, with approximately one in 10 patients having symptoms that were directly related to their heart condition. The researchers suggest that clinicians and caregivers need to be aware of possible PTSD symptoms, such as anxiety and depression, in their patients (Deng et al., 2016).

As a contrast, the following three narratives may not be as bleak as the above information and researches have stated. This may perhaps be related to their character traits, subjective perspectives, beliefs, upbringing and family environment.

The first case is from a personal friend that will be called *Sam* for anonymity, who was diagnosed with a heart defect for the first time in his adult age. The other two cases are from
individuals who were diagnosed with CHD at birth, and how they dealt with their challenges from childhood to adulthood.

**Sam’s case**

A high school friend who was in several varsity teams, and with whom I later joined a soccer team playing in amateur leagues. He is a lively, sociable and always charming person, especially with women. He comes from a diplomat family, truly enjoyed socializing, going out late and *living it up*. He has quite a healthy self-confidence, and had a wonderful childhood with a loving and supportive family.

He visited his General Practitioner due to chest pains that were plaguing him for a few days. He was immediately told to visit a cardiologist due to the severity of the situation. He was already very anxious, and seeked second opinion. Fearful thoughts overwhelmed him when the second opinion confirmed the diagnosis of his heart defect (Atrial septal defect), conclusively an open-heart surgery was inevitable. Noticing his panic, the physicians informed him, such surgeries are being conducted constantly and he has no need to worry. Collecting himself emotionally after being informed of the high chances of healing, he quickly came to terms with the situation. Crucially he did not waist any time wallowing in self-pity or contemplating on senseless questions – but being pragmatic and seeking the best heart surgeon he could find.

He had to go through two surgeries, due to some complications, but being over a month in hospital, he was cleared to leave. “I never felt so weak and vulnerable, physically and psychologically”, he told me later. He stopped smoking and drinking, for a few months. Then as he regenerated a few months later, he once again started with his old habits. When I asked him why he is not more careful after going through a crucial heart surgery, he responded:

“I know I have to be careful of a few things, like taking my medication and going to my regular check-ups, other than that I do not want to limit myself, and still like to live my life as fully as I can. Each time I feel a bit ‘weird’ in my chest, I try to relax, and know that I had the best care and nothing will happen, panicking will make it worse. So I tell myself, “take it easy, relax and know you have a tough heart, as it functioned all these years with such a defect, so ‘all is well’. I mean, at the end of the day, I think, we are all going to die eventually, and so will I – but when I do, I’d like to know that I did what ever I could to be ‘alive’ till the end.”
Diagnosis: Congenital Heart Defect

As it is evident, at this stage of adulthood, Sam did not face any severe psychological challenges after his heart was successfully operated, this is perhaps due to his character traits and confidence in this stage of his life. Therefore as mentioned earlier, facing personal health challenges can be very different from one person to another depending on their established character, life experience, views and beliefs.

**William’s case**

“I was born with a heart defect, tetralogy of Fallot, in 1954. My parents were told that I would not survive even a year. At that time, the option of surgery was new and very few doctors were skilled in this type of procedure. In 1966, at the age of eleven, I had corrective surgery. The medical care had advanced and I was very lucky. I was doing well until May of 1969, when we discovered that my heart rate was dangerously low: less than 30 beats per minute. So, on May 21, 1969, I got my first pacemaker. Again, because of new developments in medical care, I was lucky. Advances in pacemaker technology have continually improved my quality of life. Today, I am 61 years old and have an implanted cardiac defibrillator.

Due to the advances in medical care, today, children can get the care they need within the first few weeks of life. If I was born today with the same heart defect, the surgery would be done at 4-8 weeks of age. As the medical community learns and moves forward, people with heart defects have and will benefit as a result. Now, we live longer, healthier lives. However, our surgery is not a total cure, and, as we age, we still suffer effects of these conditions. Continued medical care and ongoing research is vitally important to each of our lives” (Division of Birth Defects and Developmental Disabilities, CDC.org, 2016).

Despite the odds on survival rate with CHD in the 50’s, William’s story may shed a light on his general belief of “being lucky”, that was mentioned twice in his narrative. Later, needing a pacemaker to survive did not seem to change his spirit either. This subjective perspective could have been a vital asset in avoiding psychological disorder and exacerbation of his health condition.

**Aisha’s case**

“Here is my incredible journey as a congenital heart patient. I was born with four defects in the heart called tetralogy of Fallot, commonly known as “blue baby”. In the 1960s in India, open-heart surgeries were unheard of. Uncorrected, this condition rarely survives into adulthood. At age 4, I had a procedure to help my blood bypass the problems in my heart, which helped me attend school. Trying my best to be ‘normal’ despite a long ‘do-not-do’ list, I completed high school. At age 15 my student life came crashing down, as daily school attendance became a challenge. In 1976, I was given a 5% chance of survival for an open-heart surgery. The decision
was momentous both to me and my family. The 8-hour surgery involved not only correcting the defects, but also fixing what had been done in my previous procedure. The result of the surgery was unknown for about 72 hours, but I pulled through with only a scar infection as a complication. A three-month stay in the hospital was followed by a year of a salt-free diet and no school.

Having survived the open-heart surgery (called total correction), I became a medical example. My spirit demanded an unusual education. With the doctor’s permission, I opted to become a software engineer, and took up a career in information technology. I met a man who was brave enough to take me on for a spouse. Thirteen years after the open-heart surgery, a new murmur led to the discovery of the results of the initial procedure coming undone. I was shuttled to a pediatric surgical center to fix it.

In 1992, we moved to the US and in 1997, I had a daughter – a 32 week preemie. Motherhood and pregnancy took a toll and by 2002, I began to feel breathless and exhausted. My pulmonary valve needed to be replaced. Again, it was yet another pediatric hospital and pediatric heart surgeon who fixed me. This time the survival rate given was 99% and only a week’s hospital stay!

I am one of the first groups of adults alive with this congenital heart defect. We form a new population whose healthcare needs have not yet been studied and whose prognosis and life expectancy are still unknown. Recently, I experienced heart palpitations requiring medication to slow my heart. A new unexpected defect in the left side of the heart has also come to light, making me a ‘rare’ case. Patients living into adulthood and their doctors now face the unknown. Stepping into the sixth decade of life, I realized that my heart will never be totally corrected. Hence, I will need lifelong monitoring at a specialized health clinic. My advice to others like me is to contact specialized clinics and face the unknown together with the doctors. Public health has a very important role in helping such patients with much needed research” (Division of Birth Defects and Developmental Disabilities, CDC.org, 2016).

Aisha’s story confirms that the competence of the healthcare professionals, especially the surgical know-how, as well as the relating technology has comprehensively evolved, giving CHD patients a much better chance of survival. However, to date, despite improved treatments and a successful heart surgery, many people with a CHD are not completely cured. As a person with a heart defect ages, further heart problems may occur. Additional medications, surgeries, or other procedures may be needed after the initial childhood surgeries. Some people with heart defects need lifelong care to stay as healthy as possible and address certain health issues (Division of Birth Defects and Developmental Disabilities, CDC.org, 2016). Nevertheless, despite the rigid lifelong care and discipline, the psychological wellbeing can have a substantial attribute on the quality of life in facing the day-to-day challenges.
**Conclusion**

Congenital Heart Defect is a serious condition that has negative influences on the atmosphere of a family. The physical, and importantly, psychological stress imposed on families can lead to internal disputes, and separations. It is a life-long condition and a *forced* transition for parents who have to care for their offspring with such life threatening illness. Furthermore, for a child with CHD, sensing the constant stress of the home environment as well as the physical deficiencies in comparison to other children, can add a risk of creating psychological issues in addition to the given state. With it’s etiology not fully grasped, and lack of methods developed in preventing CHD, to date it can only be encountered with improved surgical intervention.

There are however comprehensive remedies with today’s advancements in medicine, surgical processes and technologies, to deal with the physical part, as well fairly effective psychological support that are available for parents and for children. The examples and information given in this paper reveals the ongoing quest for finding and creating the appropriate support for parents and children facing the challenges of living with CHD. Despite the quantitative studies not meeting the level of effectiveness of qualitative studies, the importance lies in the constant probing as well as trials and errors that are being observed in the ongoing researches. The collaboration between the physical and psychological support is paramount. As the field of medicine is advancing, so should the effectiveness of psychological support and intervention. Due to the complexity of the human psyche, it is evident that there are needs for improvement to tailor psychological remedies for families depending on their socio-economical status, culture, background and beliefs to be able to target their daily challenges more effectively. The subjective psychological responses in the parents with their newborn diagnosed with CHD are commonly; guilt, anxiety through uncertainty and in times, rage. The professionals in the communities of psychology should target these common factors comprehensively, in order to create further appropriate programs to help facilitate more stability in the ambivalent state of such families, and moreover bring relative ease while upbringing a child with CHD.

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Diagnosis: Congenital Heart Defect

Bibliography


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