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Promoting Resilience in Families with Children with Congenital Heart Disease

Gabriella Arrien

William James College, USA

***Corresponding author**
Gabriella Arrien, William James College, USA, E-mail: garrien31@gmail.com

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Abstract

Congenital heart disease (CHD) is the most common birth defect, affecting approximately 40,000 infants annually in the US [1]. CHD involves a variety of heart defects, with a wide spectrum from simple to moderate to complex. Due to advances in pediatric cardiology and cardiac surgery, life expectancy in these children has increased drastically over the past decades. Now 90% of infants diagnosed with CHD live well into adulthood [2]. Due to the increase in survival rates, attention has shifted towards the impact of CHD on psychological and cognitive functioning [3]. Children with CHD are at risk for neurodevelopmental and psychosocial problems related to operative factors. Children with CHD display lower cognitive functioning, and higher rates in behavioral, attentional and emotional problems. Increased parental stress also adds to the psychosocial issues experienced by these children. For this reason, psychological care needed to promote resiliency in this population. Incorporating psychological services into treatment protocols with children with CHD is beneficial and will improve behavioral and emotional functioning across their lifespan [4]. This paper will review the definitions of resiliency and Congenital Heart Disease, as well as the professional roles of people treating infants with CHD, the risk factors deterring resiliency, and the developmental outcomes in children with CHD. It will then examine some of the most common psychological interventions for children with CHD and chronic illness, including CBT and psychoeducational interventions, and family-based interventions that also include a psychoeducational component. I will conclude by discussing the value of this multidimensional approach and why it is the most effective intervention strategy to promote resiliency in children with CHD.

According to Kovacs et al. "Congenital heart disease (CHD) is characterized by structural defects of the heart and/or great vessels, and is present in almost 1% of infants at birth" (p. 385). It become the most common inborn birth defect and exists in eight newborns for every 1,000 births [5, 6]. When parents find out that their child diagnosed with CHD, they can experience overwhelming emotions such as stress, anger, sadness, uncertainty, and hopelessness [6]. Rates of CHD are steadily increasing and it is important to focus research efforts on improving the management of these patients. Medical interventions bring many benefits. However, as medical protocols become standardized, there is a risk that medical personnel will potentially develop less personal and less humanized processes for treating patients [6]. According to McCusker et al. there is evidence suggesting that mothers and families of children with CHD are at a higher risk for psychological difficulties [7]. For this reason, psychological interventions that support psychological adjustment in families are vital for the child's well-being.

As result of the reduction in death rates associated with this disease, CHD now is known as a chronic disease instead of a terminal one [8]. CHD may require frequent diagnostic and therapeutic interventions, which can negatively affect the emotional stability as well as the behavioral adaptation of the child [9]. These children can display impulsive behavior and feelings of inferiority, anxiety and depression. In addition, the hospitalization process can impact the psycho-developmental processes in the child, and families find themselves having to contend with a traumatized child [6]. Little research has been done on the psychological impact of CHD, and its effects on development are not well-defined [10]. Psychosocial interventions with families can promote resiliency by lowering distress as well as improving social support and quality of life.

The following paper will examine how CHD in children affects both the child and the family. The focus will be on how the diagnosis affects the child with CHD physically and psychologically from gestation to childhood. The paper will also explore the psychological interventions that promote resiliency in these families. The first section will define resiliency and how this is evidence within the family. The next section will define congenital heart disease and its subtypes. Following these definitions, I will provide a brief overview of the process parents experience when their infants diagnosed with CHD, including the major decisions they asked to make and how the CHD diagnosis affects the mother's ability to form a secure attachment with the baby. The next section will discuss how having a child with CHD affects the whole family, followed by an overview of the neurodevelopmental, cognitive, behavioral, and emotional outcomes for toddlers and older children with CHD. Later in the paper, I will describe the most common psychological interventions for children with CHD and chronic illness more generally. There are few interventions designed for families with children with CHD but there are many interventions for children with chronic illness that can be applied to the symptoms experienced by children with CHD. There are two types of interventions: symptom-focused, individual approaches and family focused approaches. I will argue that the most effective approaches for promoting resilience are multidimensional approaches that include both family therapy and psychoeducational components. Finally, the paper will conclude by discussing areas that are worthy of future study, including the lack of specific interventions for this population.

Resiliency

According to Lee, Kim, & Choi, resilience refers to a dynamic process encompassing positive adaptation within the context of significant adversity; it is the ability to sustain adaptive functioning and positive growth and development in the face of significant stress…Resilience frames the relationships among adversity, protective factors, and positive outcomes [8].

In addition, Hamall, Heard, Inder, MCGill and Kay-Lambkin claimed that resilience-based mental health interventions can help families to define their strengths, pinpoint their protective factors, and identify resources they can use to build on within their family system and environment. As such, family-focused interventions can provide opportunities for families to practice specific strategies in improving coping and family functioning. Interventions that assist parents have positive outcomes for the child as well as the family because parental well-being and family functioning have a great impact on the child's mental health outcomes [11].

The success of an individual's coping is not dependent on the absence of distress but instead on the child and parents' perception of the event. Coping means the set of emotional, behavioral, and cognitive responses used to manage a stressful situation [12]. The individual's coping style relies on a variety of interacting factors. This includes social skills, problem-solving skills, social support, energy and health, material resources, beliefs, temperament, familial coping patterns, and developmental level [12]. These factors play into the child's and the family's coping and management of the child's CHD medical interventions. The resilience or success of the child's and family's psychosocial mental health depends on many interacting ingredients.

Congenital Heart Disease Defined

The term congenital typically means present at birth. However, when it comes to congenital heart disease, many defects may not be evident at birth and appear later in life. The definition of congenital heart disease proposed by Mitchell, Sellmann, Westphal and Park is "a gross structural abnormality of the heart or intra thoracic great vessels that is actually or potentially of functional significance" [13]. Functionless abnormalities of the great veins are excluded from this definition. The significant physiopathological aspects of the congenital cardiac malformations are the "presence of shunt (abnormal communications between two chambers or two vessels) between arterial and venous blood and presence or absence of cyanosis" [14]. In simplified terms, CHD is a structural problem with the heart that is present at birth that may disrupt the individual's circulatory system and cause chronic medical conditions. The cardiac abnormality occurs soon after conception, when the heart is developing. Certain steps must occur in order for the heart to develop normally, and it takes a total of 8 weeks for the heart to fully develop. When a crucial step does not occur at the right time, often the result is congenital heart disease. CHD ranges in severity from *simple*, such as holes in between chambers of the heart, to *complex*, such as complete absence of one or more chambers or valves.

Common Types of CHD

There are at least 18 types of CHD and there are several ways to classify them. This paper will list some of the most common types and then focus on the severe or complex conditions, which may impact the psychosocial functioning of a child diagnosed with CHD and his or her family. This paper will classify CHD into three categories so that the reader will obtain a basic understanding of CHD. The first category causes too much blood to pass through the lungs; the second category causes too little blood to pass through the lungs, and the third causes too little blood to travel to the body [14].

The first category, a group of disorders that causes too much blood flow to the lungs, includes Patent ductus arteriosus (PDA), an opening between two major blood vessels coming from the heart. The opening is referred to as ductus arteriosus and usually closes two or three after birth in children with this condition, but if this lesion remains open then it is called patent ductus arteriosus (PDA). If untreated, the baby will develop pulmonary hypertension and have an enlarged and weakened heart [1]. Another type of heart deformity is Atrical septal defect (ASD), where there is a hole in the wall that separates the two chambers and causes the oxygen-rich blood to leak in to the oxygen-poor blood. ASD is the third most common type of CHD and is usually diagnosed in late childhood or in adults. If left untreated, ASD can cause damage to the blood vessels and lungs [1].

Ventricular septal defect (VSD) is a defect or lesion between the right and left ventricles which may occur in isolation or part of a complex cardiac defect. About 85% to 90% of VSDs close spontaneously by age one (Hoffman & Kaplan, 2002). Atrioventricular septal defects (AVSDs), also known as atrioventricular canal (AV canal) and endocardial cushion defects are most common in infants with Down syndrome. In AVSD, blood flows where it usually should not go and this may lead to congestive heart failure (Saenz, Beebe, & Triplett, 1999).

The second category is the type of CHD that causes too little blood to pass through the lungs. This category includes six types: (a) Tricuspid Atresia, a lack of formation of the tricuspid valve and a lack of a direct connection between the right atrium and right ventricle; (b) Pulmonary Atresia, a defect in the development of the pulmonary valve; (c) Transposition of the Great Arteries (TGA), a defect in which the location of the pulmonary artery and the aorta are reversed; (d) Tetralogy of Fallot (TOF), a defect that consists of four problems, including a whole between the lower chambers of the heart; (e) Double outlet right ventricle, a condition where both the aorta and the pulmonary artery are connected to the right ventricle; and (f) truncus arteriosus, which occurs when a single great ventricle does not separate completely [15].

The third category is when there is insufficient blood to travel to the body. This includes four disorders. Coarctation of the aorta (Coarc). This defect easily diagnosed by detecting the upper body hypertension and weak femoral pulses [1]. The obstruction of the arch causes the hypertension. Aortic stenosis (AS) occurs when the aortic valve between the left ventricle and the aorta narrowed. Pulmonic stenosis (PS) occurs when the pulmonary valve is too tight which causes the flow of the blood from the right ventricle of the heart into the pulmonary artery to delayed. Aortic stenosis (AS) is one of the most common and the most serious valve diseases because it is the narrowing of the aortic valve opening which restricts blood flow. Children diagnosed with AS are usually asymptomatic throughout childhood and only five percent of these children develop congestive heart failure [1].

In addition to these three categories, there are several other forms of congenital heart disease. Hypoplastic left heart syndrome (HLHS) is a combination of many abnormalities of the heart and great blood vessels. Usually HLHS occurs when the right side of the heart is not grown properly. Children have to go under a series of reconstructive surgeries starting early on and extending into childhood. Another defect is the bicuspid aortic valve (BAV), which is an aortic valve with only two leaflets that should have three. This valve regulates blood flow from the heart to the aorta as well as the major blood vessels, which brings blood to the body [15].

In other cases, there can be a mixture of several heart defects, making the problem more complex, and these forms of CHD may fall into several of the categories listed above [14].

CHD in Infancy

In the past 30 years, there has been growth in prenatal imaging which facilitates early detection of single-ventricle congenital heart disease and other forms of CHD. Utilizing early detection procedures will improve prenatal care and increase care options as well as improve clinical outcomes. Early detection will enable the families to "expedite timely referral for fetal echocardiography and consultation" [16]. The advantages of prenatal diagnosis of SVCHD include having more information from education and prenatal testing, choosing a delivery location, terminating or continuing the pregnancy, and involving the neonatal cardiac surgical center. Another benefit of prenatal diagnosis is detecting the diagnosis of "hypoplastic left heart syndrome (HLHS), which is associated with improved clinical status and survival, and improved preoperative management and fewer perioperative neurological events" [16]. Prenatal diagnosis not only prepares families in understanding their child's condition by the available education during fetal care visits but also allows parents time to grieve and move through the grief stages.

There are a few types of CHDs that may be selected for intervention that will save the child's life. "A select group of fetuses may be eligible for fetal cardiac intervention for the following CHDs: (1) aortic stenosis with evolving hypoplastic left heart syndrome (HLHS), (2) HLHS with intact atrial septum, and (3) pulmonary atresia with intact ventricular septum and evolving hypoplastic right ventricle" [16].

During the fetal cardiology consultation, families are allowed to meet the staff and visit different areas of the cardiovascular program. These visits facilitate the development of trust between the parents and the team that will be taking care of the infant. Parents interested in knowing the surroundings of where their infant will be cared for after birth are able to tour the cardiac intensive care unit (ICU) Tours offer a high level of patient centered care and help families prepare and receive pertinent information about their chosen facility [16].

There are a multitude of medical and psychological variables that must be considered when working with families with children with CHD, beginning in utero diagnosis, labor and delivery post natal care and finally, helping the family adjust to caring for the infant/ child with CHD. Mothers with infants with SVCHD should be under the care of a high-risk obstetrical or maternal fetal medicine physician, and at a tertiary care hospital near the neonatal cardiac surgical program in order to allow a timely transfer of the baby and to allow family visits. The obstetrical team initializes the timing and mode of delivery, many times vaginal delivery is favored. However, if the infant is critically ill due to complications, then a cesarean would be recommended. Families who have children with SVCHD counseled about cardiac neurodevelopmental outcomes, which include developmental delays in diverse areas. There are children with SVCHD who do meet their developmental milestones on time, while others need more support to meet milestones. These outcomes are difficult to predict prenatally, and will be discussed later in the paper [16].

Mothers with infants with SVCHD may struggle with feedings. Difficulty with feeding may harm the mother-infant relationship, especially the mother-child attachment. Families are counseled about this issue, related to preoperative and postoperative feeding and nutrition, which may contribute to the psychosocial stressors experienced by the family. There are alternative methods of feeding and nourishment such as a placement of a gastrostomy tube in order facilitates the child receiving sufficient calories for growth [16].

Professional Roles of People treating Infants with CHD

Treating CHD in infants requires a comprehensive, interdisciplinary team. The professionals involved in the care of infants with CHD and their families include the "clinicians from the fetal care center, fetal and pediatric cardiology, cardiac intensive care, interventional cardiology, cardiac surgery, cardiac genetics, referring and local obstetric teams, maternal fetal medicine, neonatology, social work, and psychology along with other specialists" [16]. These specialists serve to enhance the clinical expertise in long-term prenatal and postnatal cardiac care. The information delivered to the parents must be individualized in terms of verbal and emotional responses from the mother and family members.

The study done at BCH by Lafranchi and Lincoln, states that after consultation, patients would benefit from speaking with a social worker to discuss how to cope with a SVCHD prenatal diagnosis and how to make tough decisions. Some of the decisions include; "the choice to pursue genetic testing or additional imaging; termination of pregnancy, postnatal surgery, or comfort care; fetal cardiac intervention; delivery location; and surgical center" [16].

Parents often felt that physicians should (1) ask parents about their beliefs regarding ending pregnancy; (2) show compassion and empathy and not pressure them to terminate; (3) provide more information including HLHS survival rates and support groups; and finally (4) not to mention termination if it is not an option for the family [16]. In other words, health care professionals must take time to ask their patients questions and get to know their patient's beliefs and unique perspectives, in order to provide counseling that reflects their belief system.

Psychology Professionals

Another support for the parents and families is a clinical psychologist who can provide the parents support through empathic listening as well as allow parents the opportunity to tell their stories and express their feelings. Clinical psychologists can also provide psycho education about the importance of families accepting their feelings and fully experiencing their emotions. Parents must learn to express their feelings, fears, worries, and hopes in order to adjust to the child's illness. Parents should not blame themselves for not being a perfect super parent [6]. According to Callous & Quadri, not all parents with children with CHD need consultation with a psychologist when feeling depressed or anxious about the diagnosis [6]. Formal counseling is only suggested when parents request the help and when parents are feeling overwhelmed for a longer period than the typical adjustment phase. When parents are stuck in the coping and adjusting phase or when there are additional psychological problems then consultation with psychologist recommended [17].

Psychologists can improve the parent-child relationship by providing psychoeducational interventions, which includes informing parents that the most beneficial protective factor of all is accepting and loving their child just the way they are while informing them about their condition as normally as possible. The best healing remedy for a child is that he or she should feel unconditionally loved by his or her parents [17].

Psychologists can provide support in balancing safety and warmth for the child as well as helping parents set limits and disciplining their child. Parental reinforcement of unwanted behavior may increase screaming and angry behavior in the future, so reinforcing and stimulating desirable behavior may be helpful for the child's psychosocial development [6].

Parental Coping

When parents learn about the child's diagnosis, they experience a variety of emotions. This includes increased stress, anxiety, grief, depression, resentment, uncertainty, and guilt. Parents fear the uncertain future of the child's health and the demands of learning how to care for their sick child. Parents ask common questions such as "how long will my child live, will he/she be healthy, how will the future be, and how can I take care of the baby?" [6]. Parents feel as though "their world fell into pieces" [6]. They then have to face other psychosocial stressors: difficulty with breast-feeding; financial costs which include medical, transportation and lost income; and other practical problems such as taking the siblings to day care, balancing care with work and having to take days off work [6]. These stressors can exacerbate difficult emotions.

Additionally, Parents who recently learn about the diagnosis go through a process called "working through" which is the time when they are feeling overwhelmed and confused. This time can also be described as the mourning process. Parents mourn the loss of their expected healthy child and go through an array of emotions, which takes time to process. This is a normal reaction for parents to have. The length of the "working through" may vary between parents and may be imbalanced in a marital couple, which may be the reflection of the quality of the marital relationship, or it may simply mean each spouse has a different way of adjusting and coping [6]. How families and parents cope depends on factors such as personality characteristics, quality of social support, relationship with their partner, socioeconomic status, finances and the amount of knowledge related to CHD. Taking care of a chronically ill child has been described as the most stressful experience for families. Parents of children with a recent diagnosis of CHD report relatively more stress levels than parents of children newly diagnosed with other chronic illnesses. The way parents cope with the child's situation will determine both long term and short term development of the child with CHD [6].

Children who enter hospitalization may experience separation anxiety up until toddlerhood that can persist after hospital discharge. Some of the stressors that children experience when undergoing invasive medical procedures include:

(1) physical harm or bodily injury resulting in discomfort, pain, mutilation, or death; (2) separation anxiety and dealing with strangers in the absence of a familiar, trusted adult; (3) fear of the unknown; (4) uncertainty about limits and acceptable behavior; and (5) loss of control, autonomy, and competence [12].

These medical interventions create psychosocial adjustment problems not only in the child but also in parents. Parents may become anxious and this may interfere with their ability to parent and support their child when their child is about to enter surgery or after surgery. Parents may become overly concerned about the child's physical health and may dismiss the child's emotional needs. the parent might also be missing information on the child's recovery which may lead the parent to overreact when the child shows some discomfort [12].

Long term parental stress and coping are different from short term coping. Changes may occur which are influenced by the course of the illness of CHD. A cross-sectional study done in the Netherlands included a cohort of children after at least 7 years of their first surgery for CHD. This study indicated that, in the long term, parents of these children report better mental health (less distress, less somatic symptoms, less anxiety, sleeplessness, or serious depression) and more sufficient means of coping than parents of healthy children from the general population [6]. These findings indicate that parents may develop other values after the stressful experience of the cardiac diagnosis and surgery has occurred. They might also change their views about what levels of stress and instability should be considered normal. The period of distress may have made parents stronger and worry less about the small things in life. This development is called "posttraumatic growth" which means that the "traumatized person may experience a positive psychological change due to their very stressful negative experiences" [6]. However, if the child needs to go back to the hospital for other surgeries, then parents experience renewed crises where they will have to go through the adjustment phase again.

Risk Factors

Studies have shown that parents of children with CHD of all ages evidence difficulty with forming "normal relationships" with their children [6]. Family factors such as marital status, parenting style, and maternal mental health difficulties have shown to be more important predictors of unfavorable outcomes in children with CHD than disease factors, including the severity of the disease. Unfortunately, mothers and families with a child with CHD are themselves, at risk for psychological problems, which contribute to the risk to their children [9]. Children with CHD are at risk for poor school adjustment and display "withdrawn aggressive behavior, somatic complaints, depression and anxiety" [9]. Underestimating or overestimating the severity of the disease may also have a negative impact on the development of the child.Not having enough knowledge about the child's disease may lead to knowledge gaps, which, in turn, lead to misperception regarding disease severity.

The reason for the knowledge gaps may be due to the overwhelming amount of stress and information given to the parents during diagnosis and surgery. Parents may not have enough time to process this information. Parents might also be rushed by doctors during outpatient clinics and so they may feel embarrassed to ask more questions. It is important to note that communication should be at the appropriate intellectual abilities of parents, they also need to be remind and given time to absorb the information and provided reading material. Parents of children with milder CHD have reported that they receive less attention from medical doctors and may receive less information due to less frequent outpatient examinations. Therefore, these parents may also have misperceptions regarding disease severity. This is why parents of children with milder CHD are recommended to spend time learning about their child's milder condition [6].These include developmental delays and cognitive, emotional and behavioral outcomes.

Developmental Outcomes in Children with CHD

Children with significant CHD are at risk for developing problems with cognitive functioning and behavioral adjustment [17]. While many children with CHD develop normally, about 20% fall into a clinically significant range on psychopathology. These children may struggle with depression, anxiety, attentional problems, social cognition and relationships, with an increase of problems with age. Children with milder forms of CHD have lower prevalence of neurodevelopmental disabilities, while more complex cases such as hypo plastic left heart syndrome are associated with more developmental problems due to the minor brain injury from cardiovascular compromise [18].

Other individuals have neurodevelopmental delays or complications with sensorimotor, visual motor integration, learning disabilities, and language competencies. The neurodevelopmental, cognitive, behavioral, and emotional outcomes in children with CHD will be discussed below.

Neurodevelopmental Outcomes

The spectrum of neurodevelopmental impairment in children with CHD is broad. Some children with CHD may have little to no impairment, while others are severely affected. Often complex CHD leads to surgical interventions that affect the child's neurodevelopmental outcome, such as decreased mental and psychomotor development [19].

Children with complex CHD need neurodevelopmental follow-ups because they are at a greater risk for developmental disorders (DD). Infants or neonates that require open-heart surgery, as well as children not requiring open-heart surgery that have cyanotic heart lesions, and other co morbidities are at increased risk for DD [19]. Fetal and neonatal periods are important for "brain growth, myelination, maturation, and development of neural networks" [19]. Brain immaturity and interrupted brain flow during this period leads to an increase in DD and vulnerability to injury. Infant patients may present with hypotonia that may persist in other delays such as feeding, language, and social skills. Other delays present when school demands reveal impairments, such as difficulty in calculation and other organizational issues.

For the early developmental year's ages 1-3, The Bayley Scales of Infant and Toddler Development is the most commonly used measure to assess early development such as cognitive and motor outcomes. Children who undergo cardiac surgery within the first six months of life usually have lower scores on this measure, but are still within the normal range [20]. Reports by parents noted that children with transposition of the great arteries (TGA) show poor expressive language at 2.5 years of age. There is also a deficit in motor functioning. One-year-old children with univentricle heart show a deficit in motor development, and children with hypoplastic left heart syndrome (HLHS) showed general developmental delay [20].

There are more neuropsychological measures that are valid for Children that are 4 years or older. The Boston Circulatory Arrest Study is a longitudinal study of infants who had the arterial switch operation for transposition of the great arteries. This study compares the two different surgical techniques: the circulatory arrest vs low-flow bypass. At the age of 4 years, the follow-up study revealed that the group receiving the circulatory arrest technique displayed more oromotor and facial movement abnormalities, delay in hand use and gait, and abnormalities with speech [20]. Both groups displayed an overall deficit and performed below the population norm in expressive language, motor planning and organization, visual-motor integration, intelligence and oromotor control [20].

Medical interventions such as open-heart surgery, together with cyanotic status, have also been predictive of neuropsychological deficits. Other studies reported that neurodevelopmental outcomes are compromised in children with significant CHD, regardless of whether cyanosis is present.

Cognitive Outcomes

According to a meta-analysis by Karsdorp, Everaerd, Kint and Mulder disease severity was related to overall cognitive functioning [3]. CHD patients who demonstrated decreased cognitive functioning in perceptual organizational abilities compared to the control group include patients with hypo plastic left heart syndrome (HLHS), and transposition of the great arteries. Patients with atrial septal defect (ASD), and ventricular septal defect (VSD), presented cognitive functioning in the normative range.

Severe CHD is associated with increased risk for congenital brain anomalies due to frequent surgery, physical incapacity, seizures, and pre and postoperative poor cerebral perfusion. Patients with TGA and HLHS have impaired organizational abilities compared to normative data. This detriment may be due to a decrease in motor abilities stemming from CHD and operative recovery time, which may impede normal development of spatial and motor skills. Children with severe CHD may benefit from interventions that help to improve perceptual and organizational abilities. Karsdorp et al., also found that patients with severe CHD presented lower cognitive functioning in performance intelligence than patients with less severe CHD [3]. The decreased cognitive functioning in these patients remained consistent across age groups.

Past surveys of cognitive functioning of children with CHD have shown that they have intellectual abilities at the lower end of the normal range [21]. The presence of CHD does have a detrimental effect on intelligence. This is especially true of older children with cyanotic lesions who display cognitive impairments. These impairments may be due to chronic hypoxia or physical incapacity due to the lesion and/or parental overprotection [21]. Children with cyanotic lesions may continue to show cognitive and neurodevelopmental impairment.

In a prospective cross sectional study of children and adolescents who underwent cardiac surgery, children display learning difficulties and poor concentration when compared to a control group of healthy children and children who underwent bone marrow transplantation. Children with surgically corrected cyanotic lesions displayed poorer academic performance compared to children who had heart murmurs or ventricular septal defect that closed spontaneously. The authors also found that acyanotic lesions have a good prognosis for the child's future cognitive performance. However, children with acyanotic lesions performed below their potential, despite having overall higher IQs than children with cyanotic lesions. The failure of children with cyanotic lesions to make cognitive improvements after surgery may be due to more complex disease re admission to the hospital, which interferes with academic progress and/or more missed school due to follow-up appointments, compared to children with acyanotic lesion. Academic and cognitive performance may continue to decrease as time after surgery increases [21].

Emotional and Behavioral Outcomes

For a number of reasons, children with CHD display behavioral and emotional problems. This is especially true of toddlers and preschoolers. In normal childhood development, toddlers are preoccupied with differentiating themselves from their parents and others, also referred to as the separation-individuation phase. Typically, they are immersed by ritualism (making things predictable) and negativism (gaining control over the environment). They strive for autonomy. Toddlers with CHD may experience medical procedures and/or hospitalizations as anger from their parents or loss of love from their parents. "They may react to hospitalizations by passive and depressive behavior, but also anger" [6]. The separation from parents is a key developmental task at this age, and so toddlers may have "regressive" reactions, such as children who finished toilet training who wet their diapers again after hospitalization.

Parents may have difficulty setting limits at home after pampering their child at the hospital. Parents may be inclined to give in to their child's wants because the parents feel that the child had to undergo such painful procedures. Parents may suffer from guilt that their child had experienced the surgery and in turn may experience difficulty in disciplining their child.

Toddlers with CHD will show temper tantrums, like any healthy child, and may be angry and irritated after hospitalization. Parents may worry, "is it bad for the patch in my child's heart if he/she cries and screams so firmly?" [6]. Parents will feel more inclined to give in to their child, especially when the parents may feel exhausted after such a stressful period at the hospital. Toddlers after hospitalization may show eating problems, separation problems, and sleeping problems. These problems may last several months to half a year or longer. According to a Dutch sample, "of 2-3-year-old children awaiting elective cardiac surgery or catheter intervention, increased levels of total emotional and behavioral problems were found, compared to normative data" [6].

Preschoolers may have a better time coping with separation from parents, because of magical thinking. Magical thinking is a developmental phase where they have fantasies of "mutilation or castration regarding invasive medical procedures" [6]. Proper education given to the child prior to the procedure is important.

Due to the numerous medical complications and hospitalizations that they experience, older children with CHD are at increased risk of developing later adjustment problem. The goal of medical care in children with CHD patients is now focused on understanding the impact of CHD on the psychological and cognitive functioning of the child. Factors that contribute to adjustment problems include the age of surgical repair, number of operations, associated extra-cardiac abnormalities, and medical complications during or after surgery. Children with CHD have lower self-esteem, depression, anxiety, and display more medical fears than their healthy peers [8].

A study done by Wray & Sensky noted that children with CHD considered themselves weaker, more sick and frightened than other healthy children. Children with CHD have difficulty with depression or anxiety [22].

According to LeRoy et al. children's adjustment to chronic illness (such as CHD) can be understood from a conceptual framework of stress and coping [11]. Stress happens when the relationship between a person and their environment seen as challenging or upends personal well-being [11]. These effects include the individual's emotional, physiological, cognitive, behavioral, and interpersonal changes. The physiological effects that take place include a faster heart rate and respiratory rate. Other changes include changes in skin temperature, blood pressure, and emotional responses such as depression, fear or anger. These emotions result in cognitive changes in information processing and may contribute to a pessimistic outlook [11]. As mentioned previously, behavioral changes include avoidance, resistance, soothing behaviors, restlessness and the inability to concentrate. The interpersonal changes may include perceptions of others, alterations in communication, and group functioning.

There are strategies that help an individual cope successfully. An emotion-focused coping strategy focuses on the emotional regulations of the response to stress, while a problem-focused strategy seeks to alter the stressor or external circumstance. Children and adolescents use a variety of these strategies, but there is usually a dominant pattern characterized by either approach behavior or avoidant behaviors [11].

Studies focused on emotional and behavioral outcomes in children with CHD have used the outcome measure assessing psychological functioning using the Child Behavioral Checklist (CBCL) parent form and the Wechsler Intelligence Tests for Children (WISC) to learn about the child's overall intellectual ability. A meta-analysis by Karsdorp et al., found that older children with CHD exhibited an increase in internalizing and less externalizing behavioral problems [3]. As a result, the authors suggested that such children could benefit from psychological interventions designed to reduce anxiety and depression.

A limitation of this meta-analysis is that the assessment of behavioral problems done by parents' report. Studies comparing parent and child reports have found that children report more internalizing behavioral problems than reported by parents. Therefore, caregivers may give reports that underestimate internalizing behavioral problems in children with CHD [3].

The study by Brosig et al. took place in a large Midwestern pediatric hospital in the outpatient cardiology unit where a psychologist was employed [23]. A co-located model of psychological care was used and the Child Behavior Checklist (CBCL) was completed by parents. A Teacher Report Form was completed by teachers or daycare providers that included internalizing and externalizing problems and the total score. This study included the Pediatric Quality of Life Inventory (PedsQL), which measures the parent's perception of the child's quality of life and includes items about energy level, whether the child is teased, performance at school, etc. Physical health and psychosocial health scores are also taken into account. The comparison groups are made up of children who did not have CHD, and children with CHD who received treatment at a hospital without a psychologist.

A total 79 families participated in this study. Children were referred because of emotional problems, attentional problems, behavioral problems, learning problems, and developmental delay. The results show that a large number of children had high scores on all domains of the CBCL. Children had lower quality of life, as reported by their parents, when compared to healthy children and other CHD children who were not referred to a psychologist. Only 5% of the sample was currently receiving mental health services. The psychologist recommended that 92% of the children who participated in the study should receive psychological services, special education services, or both. During the four years that were reviewed in this study, only 2% of pediatric cardiology patients who were seen at the hospital were referred for services, probably because cardiologists did not use a formal screening tool. The authors recommend that formal screening tool to use and cardiology providers should instructed to ask specific questions during psychosocial screening [23].

There was a study done with 39 children who had either acyanotic ventricular septal defect or atrial septal defect who received cardiac surgery. They were compared with a normal control group on a battery of neuro-psychological tests, intelligence tests and child behavioral checklists. There were more externalizing and internalizing behavioral problems found in the cardiac patients than the control group individuals [8].

In another study, thirty-nine Chinese children with acyanotic congenital heart disease, ages five to fourteen years, were assessed for their neuropsychological and behavioral states. What found that there was a greater behavioral disturbance in acyanotic CHD compared to controls who matched age, education level and social. Therefore, acyanotic heart disease found to negatively behavioral impact functioning [8]. Children with the cyanotic form of CHD are at higher risk of developing depression, anxiety and behavioral problems compared to those children with acyanotic heart disease. A long term psychological outcome of children after surgery (of the transposition of the great arteries) was assessed and showed that 19% of children had clinically significant child psychological symptoms, which mostly consisted of internalizing problems such as depression and anxiety [8]. Taken together, these results suggest that children with CHD are at risk of developing various psychopathologies. Thus, psychologists should become an integral part of the treatment team so that they can intervene as early as possible.

Psychological Interventions for Children with CHD

Cognitive-behavioral therapy

Behavioral and cognitive-behavioral skills are the most common techniques used for problems that chronically ill children experience. Therapists working with children with chronic illness use CBT for disease management, management of procedural distress and psychosocial adjustment problems [24]. CHD is considered to be a chronic illness, so the following chronic disease interventions may applied to children with CHD.

A study of youth with inflammatory bowel disease (IBD) used a CBT approach. This direct integration of behavioral health into medical settings proved to be beneficial among youth with comorbid IBD and anxiety [25]. According to the study, the physical symptoms experienced include chronic and unpredictable abdominal pain and urgent diarrhea as well, as disabling fatigue. Youth with IBD may experience psychosocial and academic disruptions, which exacerbates the risk of developing an anxiety disorder. Some of the anxiety experienced by this population includes social anxiety, generalized anxiety, separation anxiety, and simple phobias [25]. This comorbidity of anxiety disorder happens as frequently in this population as in other chronic medical illnesses such as CHD.

Anxiety can increase the patient's attention to physical sensations which are elevates threat appraisals of disease related stimuli. Empirical studies have used CBT for illness-related emotions and disease management, which resulted in positive outcomes. The study by Reigada et al., uses the first CBT protocol, called TAPS + IBD, to directly target the anxiety children experience that stems from their IBD symptoms [25]. The TAPS program uses cognitive restructuring, relaxation, exposure, and homework. The material was tailored to be developmentally appropriate for children ages 8-12. The program had 13 individual weekly 1 –hour sessions and two post treatment 1 –hour booster sessions [25].

The authors concluded that the active skills based approach TAPS+IBD reduces anxiety and helped youth manage emotional and the physical demands of illness [25]. The participants of the study showed immediate improvement post treatment. The findings also suggest that the treatment effects last 3-months post-treatment. The study also found that medical providers play a crucial role in the referral process of the study because about half of the families who participated in the study were recommended to participate by their physician. The medical setting allowed therapists to provide support when the child was experiencing a medical crisis. Another finding shows that families are more likely to follow through with mental health referrals when the services are provided on site vs off site. This pairing of medical management and mental health is a complimentary partnership that enables youth to be helped when experiencing emotional and/or disease management issues early. This preventive approach can offset long-term impairment in youth with IBD or other chronic diseases [25].

The TAPS+IBD study suggests that flexible health-integrative CBT for anxiety disorders that addresses illness adjustment (including associated illness-related anxiety) can ease anxiety symptoms and can improve children's emotional and functional adjustment to IBD [25]. The integration of the behavioral health approach into medical settings was helpful when intervening with youth with IBD.

Psychoeducational Interventions

Psychoeducational interventions are often a key component of CBT. They come in many forms. Some are simple information written materials; others are computer programs or the internet. Group interventions focus on training in specific disease management techniques. The holistic style of intervention (self-management) focuses on psychosocial issues, like social skills training.

In the UK there is a growing appreciation in the role of psychoeducational interventions that facilitate adaptation to the challenges of chronic disease. An article by Barlow and Ellard reviewed twelve psychoeducational interventions and their effectiveness for children with chronic disease. They found that in the UK there is an initiative in the National Health Service (NHS) Plan and the Expert Patients Program to position the patients as the experts on their treatment by accessing information and training pertaining to their health care needs. The Children's Taskforce as well as the Children's National Service Framework will guarantee that children with illness will be cared for not only for their medical, social and educational needs but also for their views and decision. The aim is for children caretakers and family members to be involved in decisions about their treatment so they can be equipped to be proactive in their role of the daily management of the illness.

A study to determine the effectiveness of a psycho-educational group intervention called Op Koers (O.K. program) for children with chronic illness was conducted. This study's goal was to empower children with chronic disease by teaching them coping strategies. The coping strategies included using relaxation, seeking information and positive thinking to increase social-emotional functioning and self worth [24]. The intervention program was based on Beck's cognitive theory "on emotion stating that everybody (including children) is processing information at all times and because of these experiences conceiving thoughts and feelings about themselves and the surrounding world" [24]. The Thinking-Feeling-Doing model (TFD-model) is used throughout the whole program in order to learn new behavior and recognize feelings and thoughts.

The O.K. program is based on skills that are effective in behavioral and cognitive behavioral therapeutic programs for children who have somatic complaints and in children with anxiety and/or behavior disorders. In the study, a total 109 patients participated from three age groups. The results of the study concluded that there was an improvement in disease related skills. At a half a year post-intervention, patients reported greater positive thinking and relaxation, as well as more information seeking than at pre-intervention. In addition, patients reported higher social competence half a year after the intervention. Other important findings of this study included positive effects on social and emotional outcomes. According to the participant's parents, the patients showed a decline in behavioral and emotional problems and fewer internalizing problems, both a few weeks and half a year after intervention [24]. Patients also reported an increase in quality of daily life.

Family Psychosocial Interventions

Nearly all interventions for children with chronic illness are geared toward disease management, such as pain control and adherence to medication regimens. These interventions often do not address the psychosocial consequences of living with a chronic illness for the child and the family. Parents with a child suffering from chronic illness are at risk of having great distress and a tense relationship with the chronically ill child. Adjustment for the child of chronic illness or CHD is a "family affair" as described by McCusker et al., which is why it is important to have an intervention that includes the child's family, especially the mother [17].

The Congenital Heart Disease Intervention Program (CHIP) is an all-inclusive brief psychosocial interventions program for mothers of infants with congenital heart disease (CHD). The program's goal is to promote adjustment and coping in mothers through psychoeducation with individualized fact-sheets, skills training to enhance mother-infant relationships within a problem-solving format, emotional processing, and sharing narratives of other experienced parents [17]. The CHIP intervention has three main goals: 1. To help parents process grief of the loss of the healthy child and to construct meaning through narrative therapy. 2. To promote the mother-infant bond related to breast-feeding, social and sensory stimulation, caretaking is important which is not only for maternal adjustment but also for the infant's neurodevelopment. 3. "To teach mothers active, generalizable, problem-solving strategies to address current worries related to having a child with congenital heart disease" [17].

The authors recruited participants from a regional pediatric cardiology unit in the UK with parents of infants born with CHD. The intervention was delivered by a pediatric clinical psychologist and pediatric cardiology nurse specialist. The intervention had 6 sessions and the training was done by the consulting clinical psychologist. A total 70/73 families agreed to take part in the study. Mothers who participated in the CHIP program showed greater positive evaluation of their situation and diminished levels of anxiety and worry compared to the control group. The infants in the program showed statistically and clinically significant improvements compared to the Control infants in the mental development scale of the Bayleys-II. This improvement is related to "early developmental indicators of language, problem solving, memory, etc" [17]. Finally, mothers in the intervention program reported fewer difficulties with introducing solids and breastfeeding rates were higher [17].

Like the CHIP program, the program called We Together-We Success Parallel Group for Children with Asthma and their Parents (WTWS) emphasizes the importance of relational dimensions which includes the parent-child relationships or relationships with the primary caretaker. The emotional well-being of the parents/caretakers has a meaningful influence on the course on disease outcome [27].

The McCusker et al., follow-up study with the children from the CHIP- Infant study was done to measure how the intervention is impacted child behavior and family functioning. Participants included 68 four and five year olds with Congenital Heart Disease and their families. The study measured Cyanotic status, cognitive functioning and absences from school and maternal worry using the maternal worry scale. Child behavior measured using the child behavior checklist. The interventions used: 1. Problem prevention, 2. Psycho-education for parents, and 3. Parenting skills. The bicycle exercise stress test was used to reassure parents that the child with CHD was able to exercise safely. An individual parental session following the stress test 1-4 weeks after the bicycle test was done to review parental experiences and review how they have been applying the skills from the problem prevention program. This study resulted in the child missing fewer days of school and improvements in maternal mental health. There were no significant findings related to the child's behavior.

This paper reviewed psychological interventions that promote resiliency in families with children with CHD. The interventions include CBT and Psychoeducational Interventions, as well as Family Psychosocial Interventions. The Behavioral and cognitive-behavioral skills are the most common techniques used for problems that chronically ill children experience. Therapists working with children with chronic illness use CBT for disease management, management of procedural distress and psychosocial adjustment problems [24]. However, these treatments only superficially address how family's children with CHD react to the child's illness, and how family members relate to the child with CHD. The psychoeducational approach toward behavioral health is toward symptom management but does not address the psychological adjustment of the child or the familial adjustment to the child's illness.

The WTWS is a two-stage intervention model. The first stage addresses self-management, knowledge about asthma and the second stage is the Emotion Management, which addresses the familial approach and psychosocial needs of the patient and caretakers (and interactions between them in response to illness).

Participants of the study were children "recruited from the Pediatric Chest Clinic of the Prince of Wales Hospital, Shatin, Hong Kong, in 2004 between the ages of seven and twelve" [27]. The result of the WTWS program showed "significant improvements in patients and their parents in symptom-related and psychological outcome measures" [27]. There were also significant improvements in measures of mental health as well as relationships between parents and children. The finding of the program supported the multidimensional intervention strategy. The individual focused psychoeducational approach combined with the relational focused family therapy approach brings a more comprehensive benefit for the child and their parents. The parents who participated in the WTWS program reported lessened burden, as well as a newly learned knowledge and skills in handling a child's asthma that can be applied to real-life situations. These positive gains were stable even after intervention [27].

The Value of the Multidimensional Approach

The Multidimensional or family psychosocial interventions approach such as the CHIP and WTWS includes a strong psychoeducational component, but also emphasizes the importance of relational dimensions, which includes the parent-child relationships or relationships with the primary caretaker. These multidimensional approach models work best to promote resiliency in families with children with congenital heart disease because they address the psychosocial aspects of family adjustment, maternal adjustment, and attachment issues with the infant, over protective parents related to the disease, as well as the trauma associated with hospitalizations and invasive medical procedures.

Conclusion

Children with CHD are at a greater risk for experiencing emotional problems, behavioral problems, developmental delays, and learning problems. In addition, addressing psychological problems in childhood is important because there is a clear link between psychosocial and behavioral health and health outcomes [23]. The better adjusted the child is, the more likely he or she will have better health outcomes in adulthood. Depressed and anxious adult cardiac patients have higher mortality rates and more cardiac complications than adult cardiac patients who do not have psychological problems [28]. This is why family psychosocial interventions for children with CHD are crucial to promoting resiliency. Children with CHD whose parents had psychosocial problems were at higher risk of rejection episodes and medication non-compliance, and were more likely to repeatedly hospitalized post-operation [29]. For these reasons, family treatment is imperative.

There are virtually no specific psychological interventions designed for families with children with CHD because there is no research for incorporating psychological care for this population. The only available intervention is CHIP. Treatments need to target specific anxieties that affect children with CHD and their families, such as fear of participating in physical activities. This is why it is important to continue research to find the best family psychosocial interventions for CHD from infancy through childhood. Another important aspect to note is the interdisciplinary team approach for children with CHD, how psychologists can play a role in the care of the child. An interdisciplinary team approach will help the staff to treat the whole person. This approach also helps with communication and the exchange of important information about the patient [30]. Some interdisciplinary teams serve to prescribe a treatment program, while others serve in a consultative capacity [31]. The team considers not only the patient's care problems, but also the elements of the system in which the patient is established. The interdisciplinary team can provide ample resources for help for the patient, family and staff. The psychosocial support for the family and child can be strengthening with this team approach. There is limited research on the effectiveness of the multidisciplinary approach. More studies need to be done on the efficacy of incorporating a psychologist or therapist in treating children with CHD.

Finally, it appears that one reason parents are reluctant to seek out psychological services for their children with CHD is the stigma associated with therapy [23]. Psychologists need to educate both providers and families about the services they offer. Merely collocating psychological services in the cardiology unit might not be enough to reduce stigma. Parents of children with CHD who endorsed items on a screening of psychosocial problems did not seek mental health services [32]. More research needs to be conduct about reducing stigma of receiving mental health services for parents of pediatric cardiology patients.

This interdisciplinary field of study is exciting because it has the potential to have innovative approaches that humanizes the treatment for children with CHD and their families. However, much more work needs to be done to ensure that this population receives care that grounded in best practices [33].

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