

# Counselling in Educational Integration of Children and Adults with Congenital Heart Diseases

Oberhuber, R. (Lecture: Physical impairments: Forms of interventions, Sigmund Freud University, Vienna)

## (1) Congenital Heart Defects

The **normal heart** is a strong, hard-working pump made of muscle tissue. It's about the size of a person's fist.

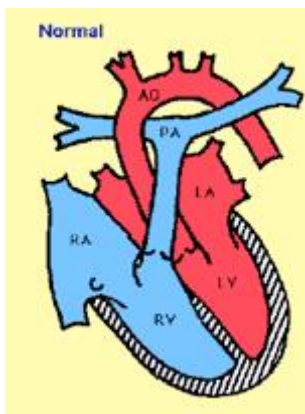
The heart has four chambers. The upper two chambers are the atria, and the lower two are the ventricles (Figure A). The chambers are separated by a wall of tissue called the septum. Blood is pumped through the chambers, aided by four heart valves. The valves open and close to let the blood flow in only one direction.

Congenital defects may involve a valve, a chamber, the septum, an artery or blood flow issues.

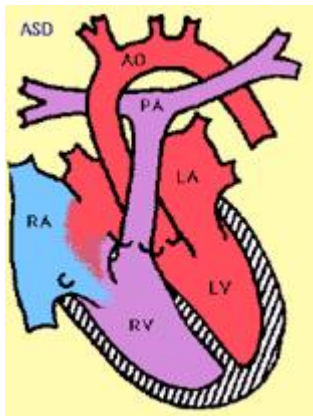
**The four heart valves are:**

1. the tricuspid valve, located between the right atrium and the right ventricle;
2. the pulmonary (pulmonic) valve, between the right ventricle and the pulmonary artery;
3. the mitral valve, between the left atrium and left ventricle; and
4. the aortic valve, between the left ventricle and the [aorta](#).

Each valve has a set of "flaps" (also called leaflets or cusps). The mitral valve normally has two flaps; the others have three (see [www.kinderherzzentrum.at](http://www.kinderherzzentrum.at))



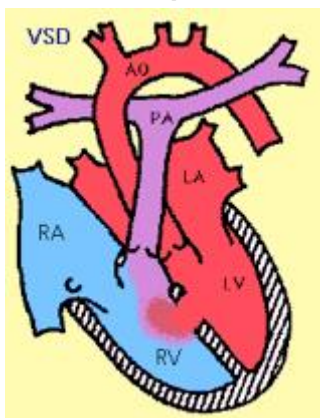
### **Atrium Sepum Defect (ASD)**



*A "hole" in the wall that separates the top two chambers of the heart.*

*This defect allows oxygen-rich blood to leak into the oxygen-poor blood chambers in the heart. ASD is a defect in the septum between the heart's two upper chambers (atria). The septum is a wall that separates the heart's left and right sides.*

### **Ventricle Septum Defect (VSD)**

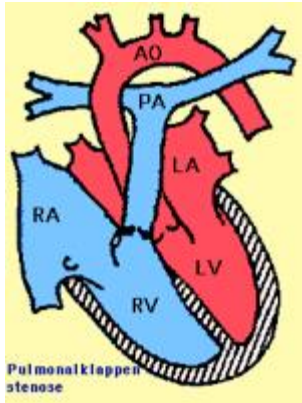


*VSD is a hole in the wall separating the two lower chambers of the heart.*

*In normal development, the wall between the chambers closes before the fetus is born, so that by birth, oxygen-rich blood is kept from mixing with the oxygen-poor blood. When the hole does not close, it may cause higher pressure in the heart or reduced oxygen to the body.*

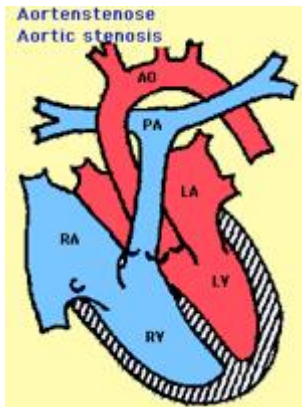
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## Pulmonary stenosis (PS)



*A thickened or fused heart valve that does not fully open. The pulmonary valve allows blood to flow out of the heart, into the pulmonary artery and then to the lungs.*

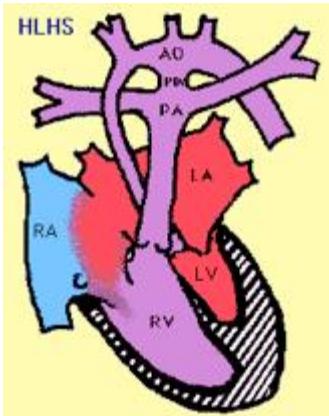
## Aortic stenosis (AS)



*A valve from the heart to the body that does not properly open and close and may also leak blood. When the blood flowing out from the heart is trapped by a poorly working valve, pressure may build up inside the heart and cause damage*

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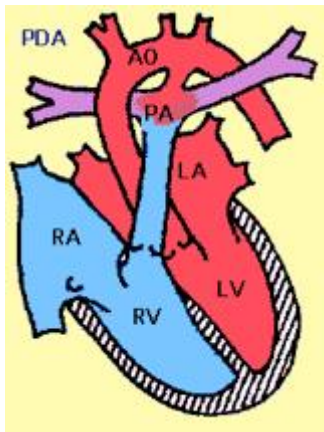
## Hypoplastic Left Heart Syndrome (HLHS)



Hypoplastic left heart syndrome is a birth defect in which the left side of the heart is underdeveloped. If not treated within days or months of birth, it can be fatal. Hypoplastic left heart syndrome can be treated with a series of operations, or may require a heart transplant.

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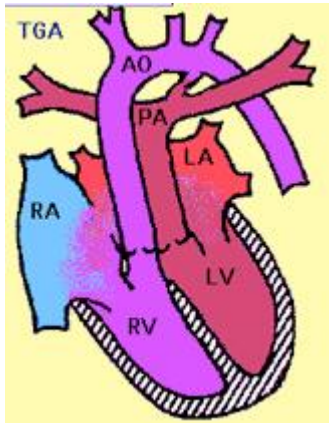
### Patent Ductus Arteriosus (PDA)



An unclosed hole in the aorta.

*Before a baby is born, the fetus's blood does not need to go to the lungs to get oxygenated. The ductus arteriosus is a hole that allows the blood to skip the circulation to the lungs. However, when the baby is born, the blood must receive oxygen in the lungs and this hole is supposed to close. If the ductus arteriosus is still open (or patent) the blood may skip this necessary step of circulation. The open hole is called the patent ductus arteriosus.*

### Transposition of the great arteries (TGA)



*A heart in which the two main arteries carrying blood away from the heart are reversed.*

*A normal blood pattern carries blood in a cycle: body-heart-lungs-heart-body.*

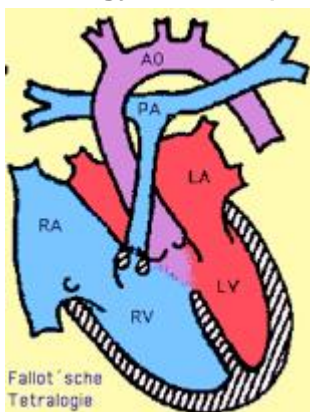
*When a d-transposition occurs, the blood pathway is impaired because the two arteries are connecting to the wrong chambers in the heart.*

This means that the blood flow cycle is stuck in either:

- *body–heart–body (without being routed to the lungs for oxygen) or*
- *lungs–heart–lungs (without delivering oxygen to the body)*

*Without surgery, the only way to survive this condition temporarily is to have leakages that allow some oxygen-rich blood to cross into the oxygen-poor blood for delivery to the body. A hospital facility can also catheterize a patient until corrective surgery can be performed.*

### **Tetralogy of Fallot (TOF)**

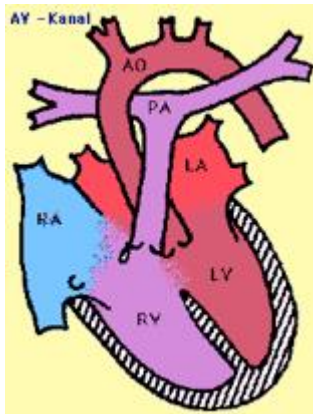


*A heart defect that features four problems.*

*They are:*

- a hole between the lower chambers of the heart
- an obstruction from the heart to the lungs
- The [aorta](#) (blood vessel) lies over the hole in the lower chambers
- The muscle surrounding the lower right chamber becomes overly thickened

### CAVC Complete Atrioventricular Canal defect (CAVC)



A large hole in center of the heart affecting all four chambers where they would normally be divided. When a heart is properly divided, the oxygen-rich blood from the lungs does not mix with the oxygen-poor blood from the body. A CAVC allows blood to mix and the chambers and valves to not properly route the blood to each station of circulation.

### (2) Children's Heart Center Linz, Psychological Care



Children's Heart Center Linz is a cooperation of general- and children's hospital Linz (now Kepler-University Hospital) and offers high quality care for children, adolescents and adults with congenital heart disease by using the latest medical knowledge. At the moment there are more than 7000 patients with congenital heart disease being cared for continuously in Children's Heart Center Linz. In 2013 altogether 389 children under 18 years of age underwent cardiac surgery.



Since 1995 optimally trained medical doctors, nurses, psychologists and perfusionists work at the Children's Heart Center Linz to enable state of the art treatment of the whole spectrum of pediatric and congenital cardiology:

- **Prenatal diagnostics** in cooperation with the department for prenatal medicine;
- **Non-invasive diagnostics:** especially echocardiography
- **Cardiac catheter examinations with interventions**
- **Pediatric heart surgery with neonatal heart surgery and intensive care medicine**

Beside prenatal diagnostics, the focus at Children's Heart Center Linz lies on the early correction of complex congenital heart disease already in newborns and infants. Special emphasis lies on the treatment of children with hypoplastic left heart syndrome, the most severe cardiac defect.

1/3 of all children undergoing cardiac surgery are newborns with altogether 2/3 of the patients being younger than 1 year of age. Children's Heart Center Linz's results correlate with the best international centers.

It is important for us to include the parents continuously by extensive information, psychological support and by enabling the co-admission of the mother or the father, as well by unlimited visiting hours.

You can also visit us on Facebook: [www.facebook.com/kinderherzzentrumlinz](http://www.facebook.com/kinderherzzentrumlinz)  
Children born with congenital heart diseases, having survived various surgical interventions and many hospital stays, experience special challenges.

On the one hand because of the permissive and inconsistent educational behavior of their parents and - on the other hand - because of excessive demands in their daily educational environment (cognitive and/or social) and sometimes also as part of the human interaction with physically healthy children of the same age.

By visiting the schools of the patients, the clinical psychologist gives significant emotional, cognitive and emphatic support to the children with heart diseases, as well as to their classmates and the teachers (also in reference to the "Selbstwirksamkeit").

Role play, giving each age group adequately worded basic information about cardiologic facts and talking about the emotionally and physically demanding hospital stays, are the core of the school visits.

In the course of these interactions, besides answering socially relevant questions being asked in a circular manner, also topics normally not mentioned and sometimes even aspects dealing with taboos are being talked about.

For example: What kind of behavior would I – as someone who has experienced many hospital stays and life threatening situations - like to see from my physically healthy classmates?

Which kind of behavior of a classmate with a heart disease would be desirable in order to better cope with this particular situation and to get better along with her/him?

Which boundaries may I set as a teacher in dealing with a child with a serious heart disease and who also has – at the same time – the moral obligation of being fair and just towards the other students? Etc...

As obviously every patient is unique in its own way, it demands a great deal of pedagogical sensibility on the part of the psychologist in coping with the respective class and its peculiar patterns and therefore shifting the focus from case to case - according to the special needs.

An empirical study about the differentiated cognitive development of children with hypoplastic Left-Heart Syndrome (Fontan) is being carried out right now at the Children's Hospital in Linz.

**(3) Psychological Research with Children with Congenital Heart Defects at the State Women's and Children's Heart Clinic, Linz, Austria - Children's Heart Clinic Oberhuber, R. (1999). Anxiety-Reducing Measures in relation to Child Heart Surgeries (Pre- and perioperative conditions of anxiety in children. An evaluation of various anxiety-reducing psychological measures.)**

**Summary First Premise**

In the United States, it has been the practice for many years to provide patients, and in particular child patients, facing serious medical procedures with pre- and post-operative psychological measures first in order to reduce anxiety and second to allow for better handling of post-operative pain and unpleasantness. The following study endeavors to update this field which in Europe has fallen somewhat into the background and, moreover, seeks a completely new form of differentiation in preparation and innovation so as to meet the demands of scientific research. Up until now, there are no comparable studies in this scope in the German-speaking world.

**Second: Study Objectives Intervention Measures**

The goal of this project was to minimize the anxiety and physical discomfort encountered by children who are facing heart surgery. Based on current scientific recognitions in the field (see Abbott 1990, Betz 1995, Block 1995, Burker 1995, Campbell 1995, Davis 1994, Doty 1997, Manyande 1995, Oxman 1995, Rasnake 1989, Salmons 1992, Saile 1992, Schmidt 1992, Stinson 1995, Wallace 1995) young patients at the cardiology division of the State Children's Clinic of Linz aged 3 through 14 engaged in different psychological preparatory measures (roll play, cognitive learning programs and coping strategies) depending on socio-demographic variables, personality factors and respective medical diagnoses. The patients' families were also integrated into the course of these measures.

**Third: Measurement Instruments**

Prior to and after receipt of preparation measures, the condition of anxiety was measured pursuant to the State-Trait-AnxietyInventory for Children (STAIC according to Spielberger 1972). Prior to being released from the hospital, patients were



evaluated by treating physicians, nurses and parents according to modified behavior questionnaires pursuant to Goldschmidt (1986) und Rasnake (1989). Furthermore, verbal and non-verbal expressions of operated children in regard to fear and anxiousness were also individualized psychological care (play therapy and [cf. Saile 1992], modeled learning, cognitive learning programs [cf. Goldschmidt, 1986; Schmidt, 1992], and coping techniques [cf. Saile 1992] ).

The realization of this study was assisted by the friendly support of Professor Dr. Beate Wimmer-Puchinger (University of Salzburg) whose friendly pro bono support was a material assistance in compiling this study, as well as the board of pediatric cardiology at the University of Clinic of Vienna, Professor Dr. Maria Wimmer, UNICEF, the Chief Physician at the Cardiac Surgery Department at the Thoracic and Cardiovascular Clinic, Dr. Donald B. Doty, Professor for General Surgery at the Bryner Clinic, Dr. Swen Swensen, and Debby Stoneman, child caregiver at the Primary Children's Hospital, each in Salt Lake City and attached to the University of Utah (psychological preparatory measures prior to surgery as part of „Service Intermountain Health Care“ in Salt Lake City are understood as a US-wide model).

#### **Fourth: Long-term economic and personal advantages for patients and for society**

Salmons (1992) study confirms the cost-reduction effects of longterm therapeutic intervention in the case of young heart patients and their families when psychological support is offered as of the time when the necessity of an operation is determined. General realization of the preparation and treatment methods as indicated in the project was achieved on a long-term basis at the State Children's Clinic of Linz.

#### **Fifth: Results**

A highly significant reduction of anxiety rates (1% level) was determined among the examined patients in both the areas of overall condition and personality factors as a result of the differentiated psychological preparatory methods measured prior to cardiovascular surgical procedures. Doctors, nurses, and parents, as well as the patients themselves,

Examination of the hypotheses made produced the following results:

1) After receiving psychological preparation, all patients exhibited significantly lower anxiety rates (1% level) than beforehand. All three preparation methods (role play, modeled learning and coping techniques) proved to be anxiety reducing, whereby the reduction of state anxiety was best achieved by the coping techniques method followed by role play and finally modeled learning, which was at least stronger in tendency. As expected, the reduction of trait anxiety was somewhat less, but nevertheless even in this regard a significant reduction was noted; in tendency (though not significantly) the most effective in this regard was modeled learning, followed by role play and coping techniques.

2) One particularly positive result was in relation to the specific percentage of individual predictors in regard to the variance in anxiety reduction. Admitting a parent to

Anxiety rates were measured prior to and after the psychological preparation using the State-Trait-AnxietyInventory (STAIC, Spielberger 1970, translated into German: Oberhuber 1997), including state anxiety and trait anxiety.

As the sample group remained small (which was already foreseeable at the outset of the study given prior operation data for children between the ages of 3 and 14), I decided after reviewing the scientific literature to use the STAIC for all patients. In the event of doubt, parents were available to help the youngest patients fill out the questionnaire materials.

The absence of a control group was a limitation. It did not appear practical to me, however, to divide the already small N=20 patient group any further. The priority of the study resided in examining efficiently administering differentiated preparation methods in regard to their efficiency. Establishing a control group in a different clinic was also rejected as the criteria imminent in various hospitals varied too greatly and could not be controlled. Therefore, attempts were made to balance pragmatic concerns with the demands of empirical research. Additionally, for me it was not ethically justifiable to take 50% of the patients aged 3-14 in a pilot project at a state children's clinic away from a psychological preparation program and place them in a control group, meaning that they would not receive any psychological preparation. Instead, a rating system was developed whereby doctors, verbal expressions of anxiety (0.679\*), non-verbal expressions of anxiety (0.795\*\*), protests against hospital stay (0.654\*), or rejection of medical care (0.689\*\*). Conversely, the correlation in the dimensions estimated by parents and children was very high in all scales. That may result from the fact that the younger patients filled out there estimation scales together with their parents. For parents with children under the age of seven, such procedure was in any event planned beforehand, whereas in the case of older children slight differences were noted which, however, in sum proved insignificant. Regarding the effectiveness of psychological preparation and psychological care, no significant correlation could be determined in all 4 evaluation groups. In tendency, however, the effectiveness of psychological preparation and care was rated by all four groups of individuals (doctors, nurses, parents and patient) on a scale of 1 to 10 as „very good“, i.e. from 1.4 to 2.5, whereby nurses and parents remained under 1.6 and doctors and patients remained under 2.6.

3) No significant differences could be found in the scope of anxiety reduction and the number of prior heart operations which patients had or had not been subjected to. Children who had already had two or three operations did not exhibit higher anxiety values than those with no prior experience. The same applied to the scope of anxiety values.

4) Similarly, there was little difference between the anxiety rates or anxiety reduction and the severity of the defects to be operated, any prior angiographies or the patients' sex. Regarding the results for 3) and 4), it seems that the possible assumption may be made that children with prior hospital stays may have learned strategies as to how to deal with the extreme situation of having heart surgery and that this may have prevented the situation from being worse than those compared with no prior experience.

5) The correlation between the following patient behaviors as judged by doctors and nurses were very high on a significance scale of 1%\* or, as the case may be, 5%\*

an 11-year-old boy wrote one year after her son's heartlung transplant in regard to the moment when her family became aware of the indication, „The discussion with the psychologist was extremely helpful. I tried to make my thoughts more positive and see that there is a purpose in everything. We were in Linz on December 3rd and had near constant dialogue with the doctors and the psychologist regarding what we were supposed to do and how everything would work... Dealing with the new situation was an enormous learning process. It was an entirely new situation for us knowing that our child could actually die at any minute....“

6) It is noteworthy that all families learned to develop special personal abilities in conjunction with this study, abilities which the affected persons referred to as a „view for the essential in life“. Study results by Simonton (1980) and Siegel (1986) stating that the efficiency of medical interventions is heightened by mental support were confirmed. The combination of medical and psychological health models (integrated model, cf. Greimel 1999) has been successfully established in practice.

the station accounted for 26.9% of anxiety reduction, psychological preparation covered another 18.9%, and cooperating with the team accounted for 17.9%. Taken together, psychological preparation and good team cooperation combined for a total variance explanation of 23.9%, while 41.8% of the variance in anxiety reduction could be explained.

The opportunity to get support in such borderline situations is something that most parents and children gratefully accept. By means of successful intervention, there usually emerges an extremely helpful relationship between me as a psychologist and the affected parties. Alongside my scientific qualifications, my own cardiac biography is highly useful in this work.

For the State Children's Clinic in Linz, the Department of Pediatric Cardiology has been able to successfully support medical intervention by means of psychological measures. Those primarily helped are children and their hoping parents and, as a secondary effect, a good working relationship between doctors, psychologists, parents and children can be maintained.

7) The postulate of providing all newborns with an echocardiograph examination has proven particularly desirable in terms of being able to secure competent cardiac diagnoses. Should this take place too late, in extreme cases the results would be incurable heart disease that might lead to lingering infirmity and later adolescent death.

Alongside the differentiated preparation methods set forth herein, the future of cardiological pediatric psychology resides in intensively caring for parents, including expecting parents who are awaiting a baby with a heart defect. As the age of children subject to heart surgery decreases, psychological support and intervention seems to increasingly focus on parents and relatives. As a psychologist, I have met many mothers and fathers who have mastered the challenges of having a child with a heart condition with incredible strength and stamina and with unshakeable optimism and courage. Alongside the surgical division, they were thereby able to significantly help their children become healthy again. These parents' attitudes were able to produce

positive results in the healing processes of their children. Alongside constant psychological support on the part of a psychologist, parents have access to the diary of an affected mother. She recorded her impressions, overcoming her fears and parental issues of dealing with a child with a heart condition. In particular in the case of heart and heart-lung transplants, parents of affected children may avail of particularly intensive psychological care. The mother of

Psychological Treatment and Support of Children with Heart Conditions and Their Families Patients at the Children's Heart Clinic in Linz, as well as their parents and siblings, receive psychological support prior to and after heart surgery, angiographs and MRI scan examinations. Psychological care is provided on a differentiated basis according to the person's respective age, personality and family situation. As a general rule, the purpose of the work is to reduce the fear associated with the given medically required surgery or medical or therapeutic procedure, to help patients better live with their heart illness and its effects and to fill the spectrum of resources available in the convalescence sector. In order for children to be able to complete the mostly lengthy MRI scan process without narcosis, and in order to prevent the necessity of prolonged hospital stays, patients receive psychological support prior to an examination.

The psychological support provided at the Kepler University Hospital, Med Campus IV is divided into preparation, emergency and postoperative care. Psychological care is offered to children as of age three and their families and siblings, which usually starts about one week prior to their arrival at the Clinic. This usually includes the following: information and play therapy according to age, tour of the Clinic (emergency cardiology unit, intensive care unit Med Campus III), meeting key personnel at each station, discussing any fears or insecurities, and addressing the situations of any brothers or sisters. During an operation, I am available to help and speak to relatives with any particularly strong fears. During precarious and especially lengthy operations, I remain in contact with my colleagues in the operating room to provide parents with better information regarding the status of the operation. After the operation, I continue to support entire „heart families“ for a few days, for a number of weeks or even for many years.

From a psychological standpoint, interdisciplinary cooperation with doctors, nurses, the bibliotherapist, pedagogues and counselors is part of normal and successful everyday operations.

Often, child heart patients receive special attention and care from their parents. Among others, some have difficulty adjusting to children their own age in school or kindergarten. In some cases, a visit arranged by me in conjunction with the „Heart Children“ self-help group is made to the respective school class to ensure successful interaction between child heart patients and their classmates. Recurring operations and cardio-medical challenges often bring patients and their families into difficult situations and thus require regular psychological analysis of the effects caused by the heart condition. Corresponding medical treatment is therefore eased by psychological treatment. For adults with congenital heart defects and who were originally treated at the State Women's and Children's Clinic, there is a successful cooperation in place with the Sisters of Mercy Hospital.

## **The language of infirmity**

### **Children with a severe heart disorder – their cognitive development and life quality**

Oberhuber, R (2017, 2019, 2020). Study conducted at the Children's Heart Center Linz, Austria  
Kepler-University-Hospital Linz

#### **Introduction**

Children and youth suffering from life-threatening and/or chronic illness speak their own language, so to say, which healthy people such as parents, siblings, teachers, psychologists, doctors, care-givers need to de-code. On the other hand the need to react and intervene pedagogically holistic to behavior and language of these children.

Up to until twenty years ago, Children afflicted with a life-threatening heart-disease (Hypoplastic Left Heart Syndrome), world-wide had no chance of survival immediately following their birth. From 1997 on, after three high-risk open-heart surgeries between the age of 0 and 4 years at the Children's Heart Center in Linz, these children are integrated in child day-care facilities and school. Since then, 149 children from Austria and Croatia have gone through this medical procedure, 85 have survived, 48 have participated in an extensive study concerning development, quality of life and inclusion in the school environment.

#### **Methods**

On the basis of standardized questioning as a qualitative content analysis according to Mayring (2003) the assessment of social skills, teacher-student-relations, individual strengths and challenges, and personality traits were surveyed. Classroom visits by the psychologist treating the children were installed / arranged in order to implement inclusive pedagogy.

By means of Wechsler Intelligence Scale of Children IV (WISC-IV) the respective total IQ index for the level of development was surveyed, differentiated by the indices language comprehension, perception-dependent logical thinking, working memory and processing speed.

Based on the Pediatric Quality of Life Inventory (PedsQL, Children Self Report and Parent Report) by Varni, a health-related quality-of-life measurement (HRQOL), the quality of life in physical, social, emotional and scholastic areas was determined, based on self-assessment and assessment of a parent; the total score was contrasted with a physical and a psycho-social (social, emotional, scholastic) score.

#### **Results**

On the basis of well-structured interviews and discussions in the class-groups with the psychologist, the characteristics of the cardiological student were analysed, based on possible post-traumatic strain due to the life-threatening illness and a high-risk heart surgery. Teacher and fellow students better learned to understand the characteristics (the language) of the afflicted child and could adequately deal with it. Follow-up contacts with the school and the patient assured the trust in dealing with one another. 43 children with HLHS, age 6,3 to 16,9 yrs reach an average IQ index of 84,53 (percentile rank 26,48). The variance shows a minimum value of 40 to a maximum value of 134. The results in language comprehension (84,09, percentile rank 25,66), in perception-dependent logical thinking (83,67, percentile rank 24,93), and in processing speed (84,54, percentile rank 23,81) correspond with the

total index results, thus range lower than the average of the population (percentile rank 26,48). In the working memory the results are minimally higher than the average: 101,8 (percentile rank 50,49). The results from self-assessment of the health-related quality of life (HRQOL) on a scale of 0-100 show a great spectrum from minimum 5,00 (social functioning) up to 100 (physical health-related summary score, emotional functioning, social functioning, scholastic functioning), with 98,44 total score. Similarities are to be seen with the parental assessment (proxy), a bandwidth from 10 (social functioning) to a continuous 100. Significant correlations show at high values in language comprehension with high assessment in the physical and scholastic area.

## **Conclusion**

The results show that patients with this severe heart impairment and their parents as well as their fellow students and their teachers profit highly from the cooperation between the children's hospital and the school. On the one hand the heart-child feels better understood by his surroundings (the others understand my language), on the other hand the school staff find it easier to better comprehend the traumata this child has experienced. The patients with HLHS at the age between 6 and 16 years can be supported and helped in cognitive and psychosocial aspects, even though, in comparison to healthy children, they average at a lower level in intellectual as well as quality of life factors, and they show differing characteristics in physical and psychosocial parameters. Remarkably enough, adolescent HLHS patients assess themselves the same in all life-quality parameters as healthy youth and youth with other illnesses (obesity, asthma, diabetes, ESRD), according to the Mellion study (2014).

### **(4) Dream of successful Life (Merl 2002), an example of good working psychological treatment to patients with congenital heart diseases**

- ▶ dream of succeeded gender identity
- ▶ dream of succeeded cultural identity
- ▶ dream of acceptable visual identity
- ▶ dream of succeeded spiritual anchorage
- ▶ dream of succeeded ecological niche
- ▶ dream of succeeded brotherhood
- ▶ dream of succeeded occupation/profession
- ▶ dream of succeeded friendship
- ▶ dream of succeeded partnership
- ▶ dream of succeeded sexual relationship
- ▶ dream of succeeded parent-child-relationship
- ▶ dream of succeeded grandparents-grandchildren-relationship
- ▶ dream of succeeded relationship to animals and plants



## **Raphael David Oberhuber**



works as a clinical health psychologist at the Children's Heart Center in Linz, Kepler-University-Clinic, Austria, as well as working in private practice and teaching as Professor of Psychology at the Pedagogic University of Upper Austria. He teaches children at the Department of Oncology at the Children's Hospital in Linz as well. As an author of his book (A)Live-Flourishing in the Face of Adversity and of some academic research publications he is active in some book fairs in Leipzig, Vienna and London. As a heart patient himself, and as a scientist, he is uniquely able to empathize and communicate with heart patients and their families and to provide them with expert professional care. He is married with two children and two step-children.

[\(https://www.oberhuber.co.at/\)](https://www.oberhuber.co.at/)