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Social Issues Affecting Families of Children with Congenital Heart Defects – Introduction and Research Postulates

Abstract: The functioning of children with congenital heart defects and their families in society is discussed rarely and too generally in the literature. Medical personnel, educators and caretakers have very little knowledge about this chronic disease and its prevalence. This lack of knowledge generates two extreme and undesirable attitudes: unjustified fear and negligence of the disease and its consequences. Both attitudes prevent a thorough understanding of the problem, in particular the aspects that influence the social life of children and their parents. As a result, the families of affected children are often left to their own devices, and they receive support only from other parents who are faced with the same problem or from non-governmental organizations. Educators, psychologists and sociologists should be encouraged to develop a cohesive support system based on reliable research results, and to implement measures that would enable young patients and their families to function better in society.

Key words: congenital heart defects, disability, children, family.

1. Families of children with congenital heart defects. Current state of research

Children with congenital heart defects and their families are discussed rarely and too generally in Polish non-medical literature. The issue is addressed by very few publications, most of which tackle only specific problems of the affected children and their families. The only comprehensive publication is *Dziecko z wadą serca. Poradnik dla rodziców (A Child with a Congenital Heart Defect. A Guide for Parents)* [Malec, Januszewska, Radziwiłłowa, Pawłowska 2007], authored by outstanding

physicians as well as parents of children with congenital heart defects. The book is a compendium of medical knowledge presented in a way that is comprehensible to the layman, and it contains valuable tips for bringing up children with a heart condition. An updated and supplemented edition of the book will be soon released. The discussed disease is also comprehensively addressed by a brochure by Elżbieta Makowiecka, Jacek Moll and Jadwiga Moll [2002], entitled “Mam dziecko z wadą serca” (*When Your Child Has a Congenital Heart Defect*). Information can also be found in several brochures and leaflets published in recent years by the Cor Infantis Foundation for Children with Heart Defects.

All of the above publications fall in the popular science category, and they are addressed mainly to the parents and caretakers of children with heart defects. The disease fails to attract nearly any interest from educators, psychologists or sociologists, and it is not the object of scientific research. The only exception includes several monographic articles exploring the psychological problems and the quality of life of children with heart defects and heart disease, penned by Magdalena Dyga-Kowalska and published in medical journals. A joint publication edited by the above author, entitled “Psychologiczne problemy dzieci i młodzieży z chorobami serca” (*Psychological Problems of Children and Adolescents with Heart Disease*) [Dyga-Kowalska 2005], is a particularly noteworthy addition to the literature. A short elaboration by Małgorzata Słomczyńska, entitled “Dziecko z wrodzoną wadą serca w szkole, problematyka kształcenia i wychowania” (*A Child with a Congenital Heart Defect in School: Problems Related to Education and Upbringing*) [2009], makes the first attempt at describing the social challenges faced by children with heart defects.

A heart defect influences not only the life and activity levels of the child, but it affects the entire family from the moment the condition is diagnosed, which is increasingly likely to take place before birth. This topic was addressed by two academic theses. The first is a Master’s thesis defended by Karolina Bawej at the Institute of Child Psychopathology of the Adam Mickiewicz University in Poznań, entitled “Problemy rodzin wychowujących dzieci z wrodzonymi wadami serca” (*Problems encountered by families raising children with congenital heart defects*) [2009], and second is a Bachelor’s thesis in education submitted by Olga Jakuć at the University of Warmia and Mazury in Olsztyn, entitled “Rodzina dziecka z wadą serca – funkcjonowanie i system wsparcia” (*Families of children with heart disease – functioning and support system*) [2010]. Both theses are available online (only fragments of the latter thesis) on the website of non-governmental organizations that support children with heart defects.

It should be noted that most people who write about research into children with congenital heart defects, including the authors of the above theses and the author of this article, have been confronted with the problem in their personal lives.

There are several reasons why children with heart defects and their families do not attract the researchers' interest. Above all, this is a relatively new problem. Rapid development of cardiac surgery in the second half of the 20th century enabled corrective treatment of even complex heart defects, but the most severe dysfunctions, such as hypoplastic left heart syndrome (HLHS), have been treated surgically only since the 1990s. Advanced surgical methods, invasive cardiac surgery, pharmacological treatment and technological progress steadily increase survival rates among children with congenital heart defects. Rapid progress in prenatal diagnosis supports early detection of heart defects and the preparation of targeted treatments, which also increases young patients' chances of survival. There are no accurate statistical data about the number of children with heart defects in Poland or the age structure of that group. Based on the results of research conducted in the early 1990s, it is estimated that 4000 children with heart defects are born each year in Poland, and mortality reaches several percent [<http://www.perfuzja.pl/anatomia-i-fizjologia/39-wrodzone-wady-serca-udorosych.html>]. Data supplied by the cardiology clinic at the Regional Specialist Children's Hospital in Olsztyn also throw more light on the problem. The hospital treats more than 3000 children, residents of the Region of Warmia and Mazury, with heart defects that need to be addressed surgically [Serduszko Foundation for Children with Heart Defects and Diseases¹. The hospital also admits children who require only pharmacological treatment. Those numbers indicate that congenital heart defects are no longer a problem that affects a minor part of the society, although it is sometimes difficult to resist the impression that this is exactly how the issue is perceived by the public.

Children with congenital heart defects and their families are also rarely addressed by humanities research due to very limited knowledge about the impact of this condition on education and social life. This aspect will be discussed at greater length in successive parts of this article.

A congenital heart defect is classified as a chronic condition which is defined by the Chronic Disease Committee of the World Health Organization as any dysfunction or impairment having one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision and care [Wojciechowski 2007, p. 27]. Social scientists, in particular psychologists, educators and sociologists, regard chronic illness as a potential stressor that changes the life situation of the child and its family and introduces new expectations and limitations that need to be addressed on a daily basis [Pilecka 2007]. This is undoubtedly a traumatic experience. The illness not only affects the family's situation, but also introduces dramatic changes to the family structure and the relations between its members.

A diagnosis nearly always comes as a shock to the parents, and the disease is a daunting challenge for the entire family [Gruba 2003, p. 166]. Pilecka [2007] rightly noted that children affected by chronic illnesses are normal children in an abnormal situation. By the same token, it can be said that the families of children with chronic conditions are normal families facing abnormal circumstances.

Social sciences literature dedicated to the **general** problem of children with chronic illnesses and their families is extensive, and it tackles various aspects of life. A chronic condition places a huge burden on the family, but the specific nature of a congenital heart defect and its consequences are rarely discussed in the literature. The characteristic features of the disease and the associated difficulties need to be described in greater detail to facilitate the development of an effective support system for children and their families.

2. A congenital heart defect as a chronic condition. Description of the disease

Chronic illnesses are diagnosed relatively frequently in Poland. According to the Institute of Mother and Child, children with chronic conditions account for 10–15% of the entire population. Congenital heart defects are among the most frequent inborn conditions which are developed prenatally and diagnosed before or during birth. The discussed condition is defined by Professor Edward Malec as abnormalities in heart structure or heart function that persist from the moment of birth. In medical literature, the definition of a congenital heart defect is very broad, and it covers:

- abnormal connections between right and left heart chambers, between arterial vessels or between a vessel and a chamber,
- abnormal function of the atrioventricular valve or the semilunar valve,
- abnormal blood flow through the heart or blood vessels, or
- abnormal anatomical position of the heart in the thoracic cavity [Hoffman, Rydlewska, Sadowska, Rużyłło 1980, p. 249].

The clinical consequences of heart defects are determined mainly by the type and degree of hemodynamic abnormalities (blood flow abnormalities), and, to a lesser extent, by the severity of anatomical changes. Many anatomical irregularities do not disrupt blood circulation and do not give rise to pathological symptoms. Heart defects do not produce identical consequences for a child's development. There are many medical classification systems of congenital heart defects, but they will not be discussed in this article. Every heart defect is different, and the diagnosis may involve the identification of the main defect with several accompanying defects. Some defects do not require surgical intervention and are treated only palliatively with the possibility of a heart transplant in the event of complications or a deterioration in the patient's condition.

Similarly to other developmental abnormalities, the causes of heart defects remain unknown. They probably involve genetic and environmental factors as well as the mother's health condition. In most cases, heart defects are caused by a combination of factors. Chromosome abnormalities, including Down syndrome, Edwards syndrome and Turner syndrome, are diagnosed in 10% of children with cardiovascular abnormalities. DiGeorge syndrome is identified in 5% of patients, and monogenic diseases, such as Smith syndrome, Marfan syndrome and Holt-Oram syndrome, are observed in 3% of the affected children. In most patients, however, heart disorders are isolated defects. The risk that the baby will develop a heart defect increases in mothers who contracted rubella in the first trimester of pregnancy, mothers with an alcohol addiction and mothers suffering from diabetes [Dangel 2007a].

According to Maria Hoffman [1989], non-genetic factors that contribute to heart defects include abnormal implantation, hypoxia during embryonic development, the impact of physicochemical factors – radioactivity and X-rays, selected medications, fever, bad nutrition and infections during pregnancy. Hoffman argues that in most cases, congenital heart defects are caused by viral diseases contracted by the mother between the 3rd and 8th week of pregnancy, which marks the beginning of heart development in the fetus. Inborn heart abnormalities are most often diagnosed in young and healthy mothers, which is why ultrasound screening should be part of routine care during pregnancy [Dangel 2007a].

Heart defects can be identified already during the first ultrasound examination which is performed between the 11th and 14th week of pregnancy. An experienced doctor using a high-quality ultrasound scanner can make a preliminary assessment of the heart structure. The anatomical position of the heart, heart chambers, the three-vessel view of the mediastinum, coronary arteries arising from the aorta and the pulmonary artery, as well as cardiac rhythm are evaluated between the 18th and 22nd week of pregnancy. The type of defect and the available treatment options can be determined after this examination. Despite the above, in more than 50% of cases, heart defects are diagnosed only after birth [Dangel 2007b].

3. Development of children with heart defects

A single model of child development is difficult to describe due to different types of heart defects. Parents can expand their knowledge of the disease by reading about the experiences of other families.

Children with heart defects are often characterized by lower height and lower weight than their healthy peers. The above results mainly from long-term hypoxia and the resulting eating disorders which usually begin at infancy and persist throughout childhood. Newborns tire easily and have to be fed small portions

from a bottle (e.g. every two hours), which turns feeding into a round-the-clock ordeal. Infants may vomit nearly after every meal. Many children have to be fed a high-energy, gluten-free and easily digestible diet with a low salt content for many years.

Children with congenital heart defects, in particular cyanotic heart defects, usually develop slower than their healthy peers. They learn to walk at an older age, and a major developmental leap is often observed only after the last corrective surgery. The affected children may learn to run or jump only at the age of several years or even in early adolescence. Young patients often require continuous and specific rehabilitation, including pulmonary rehabilitation, and sensory integration therapy.

Many children, including patients who have undergone corrective cardiovascular surgery, may have lower cardiac efficiency which significantly deteriorates a child's performance in kindergarten or school (physical fatigue when climbing the stairs, etc.).

Children with congenital heart defects, in particular cyanotic heart defects, are often susceptible to infections which, in combination with an erratic vaccination schedule and the dangerous implications of infections for an abnormal heart, further exacerbate the social problems experienced by young patients. The parents are often faced with the dilemma of whether their child should attend a kindergarten or school.

Children with isolated heart defects are characterized by average intelligence, although prolonged hypoxia can induce neurological problems. Patients with cyanotic heart defects tire more easily, they have poor concentration and slow responses, which negatively affects their school performance.

Selected heart defects require prolonged or even life-long pharmacological treatment. The administered medications prevent heart rhythm disorders, thrombosis and heart failure. A pacemaker may be required in some cases.

4. Families of children with heart defects in the society – selected aspects

At first glance, the information presented in the previous chapter does not seem to suggest that the problems faced by families that bring up children with congenital heart defects differ significantly from the challenges facing families that raise children with other chronic conditions. Disease-specific problems are described mainly on Internet forums by parents who are beneficiaries of non-governmental organizations. The relevant information has not yet been covered by research papers or has been included only partially based on the results of surveys [Baweł 2009, Jakuć 2010].

As mentioned earlier, congenital heart defects have not yet been recognized as a social issue. The affected children and their parents have to deal with the

consequences of lacking or limited knowledge about the disease as well as the fear they invoke in others. The fear may be exacerbated by medical knowledge (in doctors) or suspicions (members of the public) associated with the fact that the heart plays a major role in the human body. The heart is the “motor”, the key organ which is required for life.

The problems experienced by parents of children with congenital heart defects begin already upon diagnosis, which often takes place before birth. The parents expect the physician to provide them with comprehensive information about the condition, prospects, treatment options and assurance that the best treatment will be available. The parents want to know whether their child will develop normally and will become a productive member of society [Jakuć 2010, p. 55]. Nearly half of the families surveyed by Olga Jakuć [2010] did not receive comprehensive information about the defect or its consequences from the physician who diagnosed the condition. Most of them resorted to professional literature and the Internet in search for the relevant information [Jakuć 2010, p. 56]. The manner in which the knowledge was communicated to the parents was also inappropriate in many cases. In the cited survey, 6 out of 28 mothers have painful recollections of that moment. These are some of their remarks: “the physician performing the ultrasound exam told me to buy a coffin instead of a cot because this is not an operable condition, and children with heart defects die” [...], “the physician yelled at me and did not provide me with any specific information about the disease”, “A cardiologist from Gdańsk made the diagnosis. She told us that the heart defect was serious, and that there was no point in trying to save the baby because its life would be short and painful. She told us to say goodbye and said that they would give him medicine to relieve pain at the end of life” [Jakuć 2010, p. 56].

Karolina Bawej [2009] also reported on the “good advice” given by the hospital staff to the parents of children with heart defects. In her survey, 31% of mothers were told something along these lines: “You are still young, so have another baby as soon as you can, because this one has slim chances of survival” [Bawej 2009, p. 66].

According to Aleksandra Maciarz [2006], iatrogenic mistakes can be attributed mainly to doctors’ excessive workload and limited consultation time per patient. In my opinion, they result mainly from a lack of knowledge about heart defects and modern treatment options, as well as medical personnel’s inability to discuss the problem. Those problems were to be resolved by a handbook entitled “Standards for information and emotional support for parents of children with congenital defects: guidelines for physicians”, authored by Magdalena Dyga-Konarska and released in 2003, but the publication does not seem to be widely known in the medical community. The described attitudes of medical personnel lead to psychological demobilization, lower motivation to participate in the child’s treatment and irrational defensive behaviors.

Low levels of knowledge among pediatricians and pediatric nurses also affect the attitudes of other specialists. One of the mothers surveyed by Karolina Bawiej wrote: “Unfortunately, none of the doctors in our town knew what was the required course of action, and nothing has changed since” [Bawiej 2009, p. 88]. Similar opinions were expressed in the survey conducted by Olga Jakuć: “Even doctors are not familiar with routine procedures for children with heart defects. The doctor was afraid to stitch up a wound on our son’s head” [Jakuć 2010, p. 74]. As a mother of a boy with severe congenital heart disease, I can also recall many such experiences. When my son developed a toothache during our stay at the seaside, I had to make dozens of calls before I was able to find a dentist within a 50 km radius who was willing to admit a child with a serious heart defect. Most dentists were not even aware that such children require antibiotic treatment before a dental intervention.

My experience and the experiences of my colleagues in the Serduszko Foundation for Children with Heart Defects and Diseases also indicate that the affected children find it difficult to socialize and actively participate in the life of the school or kindergarten. Parents, in particular mothers, families and friends may also have a skewed view of children with heart defects.

As previously mentioned, parents face a dilemma as to whether their child should attend kindergarten or other group activities due to a compromised immune system and a high risk of infection. Despite those concerns, the awareness that socialization will further the child’s development or other necessities of daily life (employment) prompt parents to give kindergarten a try. I also made such an attempt. There are no clinical indications for placing a child with a heart defect in an integration kindergarten or a special needs preschool. I applied with a renowned kindergarten in the neighborhood, and I asked them to admit my 3.5-year-old son to a summer afternoon class created especially for children who would begin regular kindergarten in the fall. I told the principal and the personnel about my son’s condition and the resulting limitations, emphasizing that after corrective surgery, the only thing my son should avoid is excessive physical effort. One of the teachers refused to admit my son to her group. The principal intervened, and my son was placed in another group on the condition that I would be available during the 3-hour class. The story repeated itself when I applied for admission in other kindergartens.

We probably need scientific research to explain the fear of children with heart defects and to rationalize hidden biases behind that fear. I have shared my experiences with other parents who are beneficiaries of the Serduszko Foundation, and I know that fearful responses are common among both teachers and students. In Germany, the problem was addressed in a guidebook for teachers which contained tips for dealing with students suffering from a heart

condition¹. The fate of the discussed guidebook for Polish physicians indicates that the development of sound standards does not solve the problem unless it is accompanied by an effective system for distributing and implementing the recommended methods.

The fear of children with heart defects represents one end of the spectrum of problems faced by the children's families. At the opposite end, there is a complete lack of understanding for the actions and decisions made by the parents on account of their children's heart condition. Paradoxically, the problem lies in the fact that a heart defect is "invisible". Most children with a heart condition are classified as disabled, but their disease and the resulting limitations are usually not apparent. The affected children do not differ in appearance (except in certain cases of cyanosis) or intelligence from their peers. People who are not familiar with the disease find it very difficult to understand the nature of the children's disability, which may lead to negligence when the fear barrier is broken. Cautionary measures undertaken by the parents are, at best, regarded as overprotectiveness. My son looks like a perfectly healthy and highly active child, but due to a complex cyanotic heart defect, he has very low cardiac capacity, he tires easily and needs a lot of sleep. Excessive fatigue also leads to water retention and puffiness. At the age of 5 years, he still needs plenty of rest in the afternoon, which helps him stay awake until bedtime. I have to pick him up from kindergarten already at noon, and I have been told many times by friends and family that my overprotectiveness would deprive my son of important social skills. Fluid control is also a problem. My son takes diuretics and blood thinning medication every day, therefore his fluid intake has to be strictly monitored. Kindergarten teachers were reluctant to comply with this requirement, and most of them would tell me that my son was not thirsty. The "he will drink when he is thirsty" principle works well with healthy children, but it could be dangerous for children with heart defects. I could give many more examples of the problems that sick children's parents have to face on a daily basis. My experiences have been validated by Olga Jakuć, in whose survey nearly 80% of parents negatively evaluated social attitudes towards children with congenital heart defects and their families. One of the surveyed mothers wrote: "[...] Our society lacks any knowledge about heart defects. People are clueless about the disease, the treatment and the patients' daily lives [...]. An acquaintance once asked me if my child would be mentally handicapped for the rest of his life. People who never met someone with a heart defect have absolutely no idea about the disease" [Jakuć 2010, p. 74].

The surveyed mothers also pointed out that the parents are often stigmatized and blamed for their child's condition, which also results from low levels of

¹ Das herzkrankte Kind in der Schule – Leitfaden für Lehrer/innen, Kroschke Stiftung IDHK, Stuttgart.

awareness. “[...] This is a complete mystery for most people who are convinced that a child’s sickness can be directly attributed to the parents’ behavior and lifestyle” [Jakuć 2010, p. 74]. The majority of parents surveyed by Olga Jakuć and Karolina Bawej also pointed out to the general unavailability of professional support for children with heart defects and their families.

Conclusions

The article discusses selected problems faced by children with congenital heart defects and their families in Poland. As mentioned in the Introduction, there is a general scarcity of comprehensive studies addressing the issue. Medical personnel, educators and caretakers have very little knowledge about this chronic illness and its prevalence, and they are unable to identify the problem, in particular aspects that influence the social life of children and their parents. For this reason, physicians and educators do not see the need to implement special, scientifically recognized measures that would enable young patients and their families to function better in society.

Social responses to children with heart defects lie at the opposite ends of the spectrum. On the one hand, there is unjustified fear which results from poor knowledge, and on the other, the disease is neglected and marginalized because it does not produce apparent physical symptoms. For this reason, the families of affected children are often left to their own devices, and they receive support only from other parents who are faced with the same problem, such as the beneficiaries of the Child’s Heart Foundation (Fundacja Serce Dziecka) or the Cor Infantis Foundation. The problem is also marginalized by local authorities. A rehabilitation and counseling workshop project for the parents of children with heart defects, developed by the Serduszko Foundation for beneficiaries in the Region of Warmia and Mazury, lost a grant competition in two consecutive years because it was evaluated as an undertaking with low levels of “social utility”. Grassroots movements initiated by parents and non-governmental organizations will not solve the problem without the support of psychology and education experts.

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