



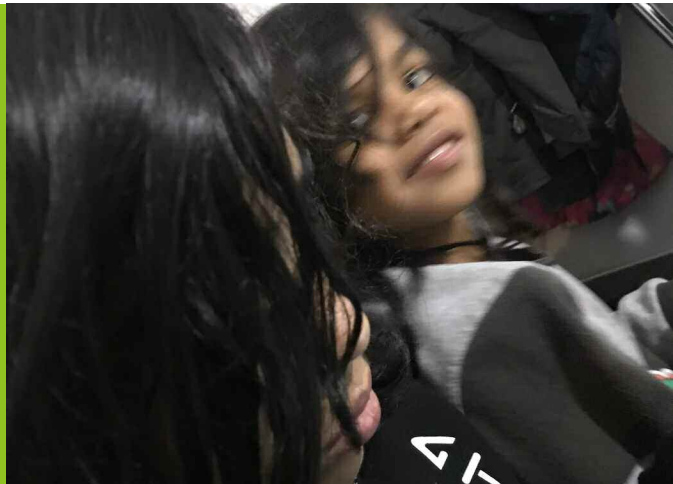
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## *Issue: Orphans and Children in Armed Conflicts*

### Original Articles

- ✓HEALTH INTERVENTION AND SOCIAL WORK PLUS EDUCATION AS JOINT PREVENTION OF SOCIAL PATHOLOGY IN ORPHANS IN LESOTHO
- ✓ANALYSIS AND SITUATION REPORT ON CHILDREN AND ORPHANS IN YEMEN
- ✓SMALL SOCIAL WORK AND VOCATIONAL INTERVENTION PROGRAM IN URBAN KENYA AND TANZANIA TO BRING THE CHILDREN FROM A STREET TO SCHOOL EXPERIENCE IN KISUMU, ELDORET, MALINDI
- ✓INCREASING PROPORTION OF MRSA IN S AUREUS AND NON-ALBICANS CANDIDA AMONG CANDIDA SPP, COLONIZING ADOLESCENT REFUGEES TO GREECE MAY BE A SIGNAL OF OVERPOPULATION OF MIGRANT FACILITIES AND CAMPS
- ✓MOTHER AND CHILD HEALTH AND EDUCATIONAL PROGRAMS IN REGIONS AFTER CIVIL WAR OR GENOCIDE-EXPERIENCES WITH MATERNITY PROJECTS IN MOZAMBIQUE, BURUNDI AND SOUTH SUDAN
- ✓POST-TRAUMATIC STRESS SYNDROME (PSS) IN CHILD VICTIMS OF WAR, AND THEIR CONSEQUENCES IN THE TEN YEAR EXPERIENCE IN LEBANON AND THE AUTONOMOUS REGION OF KURDISTAN
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- ✓FAMILIES WITH A DISABLED CHILD'S PERCEPTION OF SOCIETAL ATTITUDES TOWARDS THEM
- ✓OUT OF HOME PLACED CHILDREN IN SLOVAKIA

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# Editorial

## Children and adolescents as orphans and street children are the most vulnerable victims of economic or armed wars and conflicts

The Current issue of the *Clinical Social Work and Health Intervention* presents a series of papers devoted to vulnerable children as a potential result of social pathology in adults-real or economic war, poverty, tribal racial and national conflicts worldwide.

Post-traumatic stress syndrome may be the shortest name for this topic but not complete...Victims of war are observed not only in the Middle East, e.g. Syria, Iraq and Yemen or Afganistan..Those are victims of war with arms, but we see alot of fighting in the field of economy, interpersonal relations, tribes, streets, even in families. About one half of the parents who are alive, but due to interpersonal conflicts or poverty, their children are on streets in developing, and in orphanages in developed countries. Street children copy social pathology they see in adults, media (interpersonal) or „real,, wars and conflicts, armed or economic, cultural, social.

Therefore this issue presents result of social pathology including armed conflicts on both sides of the globe - in the developing Middle East Region suffering from 30 years lasting interstate religious or international wars, as well as social pathology in originaly „calm,,Europe, mainly the „new member states,, of the EU such as V4 members, Slovakia, Poland, Czech Republic and Hungary and also in developing states of Sub-Saharan Africa (Kenya, Lesotho, Rwanda, Burundi, Uganda, as well as Southeast Asia (Cambodia, Myanmar, India etc )

Therefore, as seen from the spectrum of authors, the probem of orphans, street children, victims of war, is truly international. Children and adolescents suffer in the conflicts, but also copy what they have seen during all kinds of this Post-trauma stress in their future lives which affect not only their lives but also their future families. Therefore, stopping armed conflicts and bringing the children back to school from the battlefields, local or interstate, religious or tribal, economic or real, is a strategic role not only for their parents and school teachers, but for all of us....

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# Health Intervention and Social Work plus Education As Joint Prevention of Social Pathology in Orphans in Lesotho

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Original Article

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## Abstract:

Joint efforts to protect adolescent girls from health consequences of HIV infection and social pathology of large urban environments celebrated its 10th year anniversary in 2019. More than 82 female orphaned children and adolescents have been receiving medical care against deadly diseases (AIDS, TB) and education. No death from HIV disease have been noted during that period.

## Introduction

Several papers in *Clinical Social Work & Health Intervention*, *American Journal of Tropical Medicine*, *Medical Horizon*, *Journal of Prenatal and Perinatal Psychology and Medicine*, *Prenatal & Life Sciences Journal*, etc., as in journals related to the prevention of social pathology, social work in the tropics, have been reporting the need for joint projects addressing social needs and social work in combination with healthcare against three major killers - HIV, tuberculosis, and malaria. Similar programs have been successful in: Cambodia and India (HIV therapy plus education); Kenya (Nutrition plus education); Uganda, Lebanon, Ukraine (HIV, TB and malnutrition). HIV and TB in migrants and homeless ventures between social work and healthcare are feasible, cheaper and require less staff than those run separately for health problems and separately for social distress (street life, street children, orphan status, substance abuse). (1-5)

## Methods

The aim of this paper is to present a report of a 10 year successful program oriented in both

fields relating to social pathology - orphan status due to deadly disease; AIDS and diseases belonging to major killers in Sub-Saharan Africa (HIV TB ).The orphanage serves for 18 female children where both parents or one died from a major killer in the South African region (AIDS, TB) in a 50,000 rural region of several villages near Maseru. Since 2009, it has been served by staff from the Dept. of Missiology John Paul School of Missiology, the SEUC Bicolored World NGO with the St. Elizabeth University Missiology program and St Cecilia Parish (Fig Photo) Habua-sono.

## Results and Discussion

Within the last 10 years more than 80 female orphans have been accepted for school and full boarding; 54 of them also due to HIV, for boarding education and healthcare. Two female humanitarian workers from Bicolored World and SEUC with local staff of teachers directly observed DOT therapy for HIV has been successfully administered for 10 years and none of children had died directly from AIDS or TB or other opportunistic infections. Joint program-educational



Author: Augustine Mahlaku

tion-healthcare plus prevention of social pathology (orphan status, street childhood) was amalgamated into one functioning program resulting in inclusion of adolescents either back to their incomplete or surrogate families, or directly to high school or work training in the neighboring (50 km border distance) capital city of 200,000 inhabitants for studies or work in RSA. Before this, similar programs in Ha Buasono had been run by the same team in Kenya, Uganda, Ukraine, Greece, Cambodia or India in 2002-2010 (6-12).

## Conclusion

In conclusion, orphan status may be surprisingly protective in early detection of three major killers – HIV, TB and Malnutrition because full boarded orphanages offer apart of medical care, free education and free food as prevention in anti-malnutrition strategy, combating together 3 major UN goals in Sub-Saharan Africa - nutrition, health, education, combined in one program.

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# Analysis and Situation Report on Children and Orphans in Yemen

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## Abstract:

Situation report on children and women as victims of bombing attacks within armed conflict and war in Yemen is analyzed.

## Introduction

A catastrophic war is destruing Yemen for almost five years. Millions of people are impoverished, Infrastructure is badly damaged and hundreds of thousands infected with cholera. More than 24 million people (80% of the population) need humanitarian aid. Children are dying on a daily basis from bombing or starvation. The UN reports that more than two million children are malnourished, with one in two now suffering from stunted growth because of food shortages. Education has been shattered, leaving 3.4 million out of school. The result is a child protection crisis with an estimated 7.4 million children in need of urgent help. According to figures released at the end of 2019 by UNICEF, on average one child dies every 10 minutes owing to preventable diseases such as malnutrition, diarrhea and respiratory infections.(1-6) More than 2.2 million children are in need of urgent care, and at least 462,000 suffer from severe acute malnutrition - a drastic increase of about 200% since before the war. (7-10) An Arab coalition led by Saudi Arabia launched a military campaign in March 2015. Since then, hundreds of thousands of Yemenis have been killed by airstrikes and starvations and millions are displaced, the UN says.

## Situation Report 2019

The coalition (UAR,SA) has been responsible for several attacks on medical centers, including some run by the international aid group *Doctors Without Borders* (MSF), schools, factories and homes which have killed hundreds of thousands of civilians. The Houthis have besieged Yemen's capital city Sanaa and second largest city, Taiz, and have been also blamed for shortages of food, water and medicines. They have also been accused of recruiting hundreds of child soldiers. Of all the different groups of people in Yemen, it is children who are by far the worst affected by this war. In the chaos and cruelty of Yemen's war, boys are being recruited to fight in it. The Houthi rebels have child soldiers as young as 11 in their ranks, according to the United Nations. Airstrikes by the Saudi-led coalition have hit children, too, like the 40 killed in August 2019 when a coalition bomb was dropped on a bus full of little boys. And then there is the menace of starvation. Millions of Yemenis are on the brink of famine, as the coun-

try's fragile economy has collapsed in this war. Over 200,000 children have already died of malnutrition and preventable diseases, according to the charity *Save the Children*. Nearly 14 million people are at risk of famine. Parents are witnessing their children waste away, while vehicles transporting food are targets of attack. Five million children are out of school and are at risk of exploitation and abuse. The children of Yemen have been robbed of their basic rights to life, health and education. The war in Yemen has hit hardest those who are least responsible – children. Facing violence and with many forced to flee their homes, Yemen's children are struggling in the face of a national economic crisis, widespread malnutrition and the grave threat of cholera and other life-threatening diseases. Recently 12.3 million children are in need of humanitarian assistance.

According to the humanitarian organization *War Child*, the situation of orphaned children is even worse. The *Dar Ri'ayat al-Aytam Orphanage* in Sanaa has been struggling with a lack of funds since Houthi rebels captured the capital in autumn 2014, and the situation has worsened since then. *Dar Ri'ayat al-Aytam* is the oldest orphanage in Yemen. It opened its doors to boys in 1925, and moved from Sanaa's ancient Old City to this spot in the 70s. Now around 400 boys call it home, some sent here by extended family, others abandoned by their destitute parents or taken in from the streets.

Abdullah al-Hindi, the head of the orphanage, said that almost five years of war had decimated the economy, and there have been severe cuts to public spending. Fadel al-Qahtani, a child living at the orphanage, spoke of dire conditions, adding that on most nights the 400-plus children



Author: Alex Topolska

housed there would go hungry. „We used to have complete meals, including stew, fruit and meat - there were even extras to go around. But now, we don't get anything other than rice,“ he said. After almost five years of war, orphans in the Yemeni capital Sanaa have only one dream - to survive. The *al-Shawkani Foundation for Orphan Care* is located around 100 meters from the al-Nahdain mountain, widely believed to be an arms depot that has been repeatedly bombarded by Saudi-led coalition's fighter jets. In March 2015 after the war erupted, bombardment of the explosive-laden peak mountain sent huge mushroom clouds (like nuclear explosion) erupting into Sanaa's skies and shook the whole city. As the war rages on, the orphans suffer through a constant state of fear and trauma. “We were scared, and every time we hear the plane's noise, they (orphanage staff) would rush us quickly to the basement fearing for our safety,” said Mousa Saleh Munassar, 14 years.” Nine-year-old Abdulaziz Badr al-Faisari of the orphanage said he and his fellow orphans were terrified when bombs shook the whole building, but appeared resigned to his fate. “We have had nowhere to flee.” As the civil war in Yemen enters its sixth year, many children who have lost or been abandoned by parents have suffered the most, both physically and emotionally. Little Mohsin Douma's father was killed in Yemen's current, brutal civil war. He is 12 years old and arrived with two older brothers to the orphanage.

*Jane Ferguson*, an award-winning international journalist and Special Correspondent for *PBS NewsHour* in Yemen brings information about the recent daily situation in the Sanaa orphanage. As she explains in the Arab world children are often considered orphans when their father dies. In Yemen, impoverished by the war, single mothers cannot cope financially. Some are forced to remarry and start new families. Ahmed, child from orphanage is 11 years old and lost his father also fighting in this war. When we asked what happened to his father, he simply says the Arabic word for airplane. Ahmed hasn't been spared the experience of war. He, like so many of the children here, has seen too much already. “Fighter jets used to bomb, and farms were exploding. And next to our house, there was bombing. Things were exploding and burning.” The other boys here tell me of the times the airstrikes

hit near the orphanage, and they were terrified. „When the airstrikes come, we pray and ask God to save us,“ one of them reports. At times, the war outside the orphanage walls has come dangerously close.

## Conclusion

Most vulnerable population attacked by bombing during tribal armed conflict and war related air strikes are children and mothers. Malnutrition and outbreaks of cholera and diphtheria are the most acute catastrophic results of this tragedy of people in Yemen.

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# Small Social Work and Vocational Intervention Program in Urban Kenya and Tanzania to bring the Children from a Street to School Experience in Kisumu, Eldoret, Malindi

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## Original Article

2nd St Philippe Neri Street Boy Center Kisumu, B1 Zdenka Schgelling and St. Kizito Educational Center, Nairobi, St. Bakita House Eldoret, St. Francis School Malindi, Anti-street Boy Initiative Mother St. Theresa Brothers Kibera, St. Philippe Neri Schools in Joshka, joint program of Slovak Aid and SEUC. St. Elizabeth University Tropical Social Work Program, Sisters of Mercy Muhuroni and Naivasha Maternity Hospital, Bicolral World NGO Bratislava, Slovak Aid Ministry of Foreign Affairs Grant Program, Rep. of Kenya.

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## Abstract:

Joint programs combining full board and education (housing and school) in Kenya are more and more popular. Results of the 15 year history of 5 programs focused on shelter and education to combat social pathology as social work intervention are presented. This communication is dedicated to Dr. Mimi Bihariova, former SEUC and SCM PhD Programs and MSc programs who died tragically in Tanzania having devoted her life in support of orphans and street children in Sub-Saharan Africa.

## Introduction

In 1999, the Sisters of Mercy started a large intervention to help street children suffering in the slums and streets of Nairobi led by Sister Mary Kileen, called „Nairobi Mother Theresa“. Over the last 20 years at least 5 independent projects similar to Mukuru Promotional Vocational and Educational Centers have been established by Slovak students of Social Work and Community Health PhD Programs in Kenya, Uganda Tanzania and Somalia, and currently running at least 5 centers where a combination of vocational education with sheltering and full board prevents street children from social pathology and brings the children from streets to schools. (1-5) The aim of this short communication is to present a brief overview of aims and effectiveness of some of these programs in the Republic of Kenya.

## Overview of the programs and their history and effectiveness

### 1. Eldoret

St. Bakita House is the oldest project to bring children from the street to school outside of Nairobi. Established in conjunction with St. Lesley Clinic in poor parts of HI Spiris Parish by the Parish Priest Fr. Martin Cingel, the clinic was transferred to the Diocese of Eldoret after 15 years of continuous work. But St. Bakita House, built in 2006, is still operated by the SEUC Tropical Social Work Program; empowered by the NGFO Biloroal World; supplied by a primary grammar school established by a Bicolored World Slovak Aid Grant. The vocational school in St. Bakita House serves from 18-24 orphans or female street girls who receive 2 years vocational training in waitering, cooking, tailoring, hairdressing programs.



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## 2. Kisumu

2<sup>nd</sup> St. Philippe House Kisumu, established by the Salesian Brothers in 2015, cover housing and shelter together with sports training and basic education for about 20 „low threshold“ street boys from streets of Kisumu (about 200,000 population).

## 3. Muhuroni and Naivasha

The anti-malnutritional program converted to education and sheltering, was again converted to an outreach nutritional program since the children have been returned to their original families. After 10 years of history, it is currently supervised by SEUC MSc Social Work students and the Sisters of Mercy. The *Naivasha Shelter* was converted to a Mother & Child Healthcare Clinic; then developed to a full Maternity Ward served by a Slovak Medical Doctor, sunned by Sisters of Mercy in Kenya who were founders of the program „Bring the children from street to school“ in 1999.

## 4. Malindi

The Malindi Program was established together by the St. Francis Sisters of Mercy plus the Franciscan Parish, and served originally as a Healthcare Center. Later, it was converted into a school plus anti-malnutrition program; then to a project supporting shelters and housing for poor families in the outreaches of Malindi. This is one of the most multifunctional programs supporting sheltering, housing, HIV program outreaches; anti-malnutrition program; primary school program to help poor families and their school children; has 12 years history. After being established it was given the name *Ushurikiano* (Place of Joy) currently serving financially handicapped households (support to about 24 children and school children) in cooperation with Healthcare by St. Francis Order Nurses and Franciscan Parish Priests in Malindi.

## 5. Nairobi

St. Kizito and BI Zdenka Vocational Center

Two small vocational full board shelters serving approximately 15 boys and 15 girls are run separately by SEU as joint interventions with St. Elizabeth University, Catholic University of South Africa and the Slovak-Kenyan BSc Program. Amalgamated after a 20 years history they

are the oldest full board shelters for street children in Nairobi. Nowadays, students are receiving education either separately in the largest school project in Kenya, the St. Philippe Neri School in Joshka founded by Kenyan MSc and PhD students. It is currently funded by Slovak Aid Grants, and a small Healthcare Center with a Slovak Physician from the SEUC Tropical Program from Bratislava SK EU.

## 6. Kibera

The Kibera Program is not a typical vocational or educational project. Some street boys are receiving special attention from the Street Boy Team chaired by Fr. Ivan Duris from the Missionaries of Charity Brotherhood a male order founded by HI Mother Theresa. It is taking care on street boys in the greatest slums in Africa Kibera having more than one million overcrowded population. The primary intention of this program is to provide food and to separate the street boys from substance abuse (mainly glue, etc.). Those successfully reintegrated from the substance misuse are offered several long term programs in a Vocational School nearby including those above mentioned. *The Bosco Boys*, the Salesian Project for reintegration of street boys is empowered by many EU Salesians co-working with social work students and volunteers.

## Conclusion

To bring the children from street to school requires tremendous effort, where the students of social work and volunteers together with local community try to prevent social pathology related to street substance abuse, prostitution, crime, etc. (6-8) If the children receive proper housing, nutrition and basic healthcare, they can be included in some of the educational programs (vocational school, primary schools, etc.) to build their futures. After completion of secondary school, the best students are offered a BSc Social Work Program - a joint degree program of SEU and CUEA (Catholic University of East Africa and St. Elizabeth University Program) established in 2001. Many of the graduates work with street children within international or national NGOs as part of circular social work and health interventional strategies in large urban environments in East Africa.



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# Increasing Proportion of MRSA in *S aureus* and Non-Albicans *Candida* Among *Candida* spp, Colonizing Adolescent Refugees to Greece May Be a Signal of Overpopulation of Migrant Facilities and Camps

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**Abstract:**

Emergence of MRSA among *S aureus* isolates may be a signal of deteriorating hygienic conditions and other public health problems in facilities, suffering from overcrowding, such as prisons, camps, orphanages, nursing homes, etc. Emergence of Non-Albicans *Candida* in addition to overcrowding and humidity, may be a signal of overuse of local or systemic antifungals and antimicrobials, both risk factors in large concentrations of potential patients and social work clients. The aim of this survey is to analyze continuous increases of a proportion of MRSA among *S aureus* and Non-Albicans *Candida* spp among yeasts in refugee camps on the Greek / Turkish border. The results suggest a shift in *S aureus* from MSSA to MRSA (12.5% to 50% in 5 years) and Non-Albicans *Candida* spp from 12.5% to 100% in 2019) which may indicate a worsening in the public health situation due to overpopulation of some refugee camps on Aegean Islands.

**Introduction**

Refugee and migrant health deals with serious public health problems due to a 5 years migration crisis in the EU mainly in Italy and Greece, where the majority of migrants enter the EU on boats and stay in refugee camps until their asylum process is facilitated. Currently, refugees from Iraq and Syria are being replaced by adolescents from Afghanistan and Sub-Saharan Africa, including minor children and their families. A marker of overcrowding and other public health problems are at least two organisms, *C albicans* and *S aureus*, which are transmitted by hands, kissing, towels, all with daily and casual contact, and are markers of overpopulation in prisons, camps, orphanages, nursing homes (1-5). The aim of this survey was to analyze changes in etiology of respiratory and skin isolates of *S aureus* and *Candida* spp, in victims of war, mainly minors, escaping from Middle East to the EU via the Balkan Route (Greek / Turkish border).

**Patients and Methods**

From 2015 (Mainland Greece - Veroia) until 2019 (Lesbos Island) bacterial isolates from skin swabs and respiratory tract from minors were analyzed for antimicrobial susceptibility. Of 233 strains from 102 minor adolescents and their family members, isolates were obtained and transported to the Natural Reference Lab of ATB Resistance in Nitra in Amyes. The liquid medium was analyzed for phenotypic antimicrobial susceptibility; years 2015-2019 were compared.

**Results and Discussion**

The proportion of MRSA among *S aureus* increased from 12.5% while clients localized in an open refugee camp in Veroia and Alexandria in mainland Greece to 25% in 2017, 50% in 2018 and 2019 (Lesbos); which means that one half of all *S aureus* strains isolated from skin wounds and respiratory secretions of refugees were resistant to all betalactam antimicrobials (MRSA).

In addition, the proportion of Non-Albican *Candida* spp (*C tropicalis*, *C parapsilosis*, *C rugosa*, *C kefir*, etc.) among all *Candida* spp increased from 25% in 2015-2016 to 100% in 2019, an indication a major shift from *C albicans* to Non-Albicans *Candida* spp. Both findings may indicate public health problems from overcrowding, overpopulation, deteriorating hygienic conditions among populations of refugees in 2019 in comparison to 2015-2016. While in 2015-2016, the population studied was in open camps on mainland Greece, in 2018-2019 all isolates came from the semi-closed camps on Lesbos Island which had been reported as overpopulated (original capacity of 4,000 has been increased to more than 10,000 in 2019). Similar shifts related to either overcrowding or misuse of antimicrobials and antifungals have been described in prisons, orphanages and nursing homes. (2-5) Another reason may be a change of the spectrum of geographic origin of the adolescents, from Syria and Iraq, in favor of e.g. Sub-Saharan Africa, where Non-Albicans *Candida* spp is more common.

## Conclusions

In conclusion, monitoring of etiology and antimicrobial susceptibility in micro-organisms colonizing or infecting refugees is mandatory, and those colonized with MRSA and other MR organisms e.g. colimycin or carbapenem resistant enterobacteriaceae should be registered and those findings have to be recorded both in the health-care systems for refugee migrant facilities as well in patients' personal health records before being transferred to mainland Greece or to other EU countries. When symptomatic disease e.g. wound infection appears cohortation of those patients is advisable.

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**Table 1** Proportion of MRSA among refugee minors and adolescents and their families in mainland versus islands of Greece

Years	2015	2016	2017	2018	2019
S aureus all	8	5	5	14	20
MRSA	1 (12.5%)	1	1 (20%)	7 (50%)	10 (50%)
Candida spp.	8	16	14	4	4
Non-Albicans C	1 (12.5%)	4 (25%)	7 (50%)	3 (75%)	4 (100%)

# Mother and Child Health and Educational Programs in Regions After Civil War or Genocide-experiences with Maternity Projects in Mozambique, Burundi and South Sudan

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## Abstract:

Maternity programs in Sub-Saharan Africa are goal directed strategies to decrease neonatal and maternal mortality and improve mother and child health in early childhood to decrease under 5 mortality. Here we present an overview of programs focused on maternal and child health in countries after civil war or genocide where impact on mother and child was most tragic and visible. Mother and child projects in Mozambique, South Sudan and Burundi, affected by 30 year of civil unrest and/or genocide are presented.

## Introduction

Women and children are the most vulnerable population to war or armed unrests (e.g. civil or tribal war and/or genocide). They are not only afflicted with post-traumatic stress syndrome but also, due to the lack of vaccination; medication supplies; weak healthcare infrastructure; disrupted transport; insecurity; healthcare may not function at all. Therefore, mortality in children under 5, neonatal as well as maternal mortality, may increase and lack of vaccination also may catastrophically affect succeeding generations. Therefore countries with long lasting civil war (e.g. Angola, DR Congo, Mozambique), or genocide (South Sudan, Burundi, Rwanda) may benefit from maternity programs (1-3) focused on major UN Millennium and currently New Century goals-to decrease neonatal and maternal mortality as well as combat 3 major killers in children under 5 – TB, HIV and malaria. (4-9)

## Overview of programs focused on maternal and child health

### 1. South Sudan

The oldest St. Elizabeth University Tropical Program had started in 1999 in South Sudan during the civil war. It has celebrated 20 years in the Mapurdit Hospital, extended in 2009 to Gordim, supported by Slovak Aid Grant where a new maternity ward was built and is operating.

### 2. Burundi

Buraniro and Gasura Hospitals are served by humanitarian staff from SK or UA including a doctor. Since 2010, part of acute care (cesarean sections) also includes preventive anti-anemia and anti-HIV programs operated by local staff.

### 3. Uganda

Since 2015, in Buikwe, preventive MTCTP anti-HIV programs and a new program for anti-parasitic preventive therapy against anemia and malnutrition are onsite and are reported separately.

### 4. Mozambique

The newest program is focused to MTCTP, pregnancy consultations and dehelminthization (deworming) strategies, started in 2019 in a rural area of Beira province, heavily affected by 30 years of civil war.

## Conclusions

Major killers affecting maternal and neonatal mortality are perinatal pathology, and delivery complications including bleeding, eclampsia, sepsis, followed by 3 major subacute and chronic killers - Malaria, HIV and TB. Another important goal has to be included in preventive strategies in maternal and child health-prevention and end of anemia a multifactorial devastating disease in tropical areas of Sub-Saharan Africa. Those long term strategies are all operated by the above mentioned projects and include intermittent preventive programs for malaria and screening for HIV and TB in a joint program, and finally dehelminthization of children for containment of chronic anemia associated with educational malfunction and socio-psychological late consequences for the whole civil society.

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# Post-traumatic Stress Syndrome (PSS) in Child Victims of War, and their Consequences in the Ten Year Experience in Lebanon and the Autonomous Region of Kurdistan

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Original Article

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## Abstract:

Early and late consequences of armed conflicts in Middle East are managed by several NGo projects in affected or adjunct countries. Here we report programs focused on minors and mothers affected by civil war (DASH - IS conflict) in Iraq with refugees to Syria Lebanon and other ME countries.



## Introduction

Early consequences of armed conflicts include acute war injuries such as crush and blast syndromes, burn and shot wounds leading to fatal organ failure and septic shock. Indirect victims suffer acute posttraumatic stress syndrome (PSS) plus acute dehydration and acute malnutrition due to food and water supply disruption. Chronic consequences include depression, diabetes, asthma, hypertension, and other cardiovascular and endocrine disorders related to acute or chronic stress.(1-8)

## Overview of projects

### I. Project focused on children belonging to Yezidi marginalized population (Kurdistan )

The Yezidi population has been worsely affected by DASH-IS expansion in Northern Iraq, with massive migration of refugees to the South Autonomous Region of Kurdistan the first safe place for Yezidi families.

The *Bl Popieluszko Clinic* in Irbil did daily outreach to Yezidi families who were on streets or very provisional shelters, serving food, water and basic medications in the city of Irbil. Outreach has been performed since 2015 by Polish/Slovak groups of doctors and volunteers of the STEP-In NGO, supported by the US Columbus Foundation, Polish Catholic Charity and Slovak Aid Grants.

### 2. Project for families of 1.2.3 generation of refugees Beirut (Lebanon)

St. Charles Foucauld Clinic operated by Little Sisters of Jesus for 30 years has been serving all 3 generations of refugees from the last 40 year Iraqi, Syrian and Palestinian armed conflicts.

In 2010, the SEU Refugee Program started healthcare treatment against post-traumatic stress syndrome and related disorders such as hypertension, coronary heart disease, diabetes mellitus, respiratory infections performing both outreach to families and running OPD with two empath nurses and 3 physicians serving yearly about 7,500 patients a year.

In the last 2 years communicable diseases (RTI UTI etc..) have been fully replaced by PSSD related disorders such as hypertension, diabetes etc.

## Conclusions

Fortunately, ending in 2018 acute conflicts in Iraq and in December 2019 also in Syria have been terminated and temporary peace started. Therefore the second phase of healthcare-rehabilitation of healthcare structures and systems will hopefully start soon in the region. These will include outpatient services for non-communicable disease with joint programs for both children and elderly, the most two vulnerable patient groups who suffer from armed conflict.

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# Quality of Lives & Origin of Unaccompanied Minors & Migration to Europe

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## Abstract:

Migration of minors has a lot in common with the migration of adults as well as a few features related to the vulnerability of the under aged. The principal subject of the research is a comparison of official statistical documents concerning the asylum system and the quality of lives of unaccompanied minors in the process of their admission into Greece and Italy which are the first-line migratory inputs, the period analyzed is the year 2018/2019. On the basis of the UN Charter, international organizations deal with the minors needs, emphasize the principle of universality of children's rights.

## Introduction

Arrivals of unaccompanied minor migrants continues increasing. The phenomenon becomes being complex regarding the number of underage migrants looking for asylum in the two countries that are affected by migration in the greatest extent, namely Greece and Italy. Just like adults, children face horrible journeys and experience stress, which occur during the three stages of their escape. The initial experience is in the country of their origin, then during their passage to the safety and the final one is the arrival and reception in the host country. The conditions of reception in the Greek islands are; however, currently very humiliating and inhuman. Migration of minors has a lot in common with the migration of adults as well as a few features related to the vulnerability of the underage (1-3).

## Methods

The principal subject of the research is a comparison of official statistical documents concerning the asylum system and the quality of lives of unaccompanied minors in the process of their admission into Greece and Italy which are the first-line migratory inputs, the period analyzed are the years 2018/2019. The situation in 2018/2019 is compared by studies which are illustrated of cases from a similar period.

## Results and Discussion

The main domain or in this case, poor quality of unaccompanied minors is based on the disturbed life as well as the influence of all pathological conditions in the reception centers of both countries. The unaccompanied minor migrants have damaged health affected by psychosocial as well as social suffering (4-10). The decisive factors for the health of migrants are largely determined by the availability, accessibility, acceptability and quality of services in the host country. On the basis of the UN Charter, international organizations deal with the minors needs, emphasize the principle of universality of children's rights. However, the reality in the reception facilities of the host countries is different. Therefore change of this process must be initiated within UNHCR and the EU agreement.

The impact borders of the EU concerning health/social care to migrants was analyzed through research Specifically, the impact of bor-

der closure on the health risks for the population at recognized reception centers in Sicily, Italy and Greece. The research was carried out in Greece with 300 respondents and in Sicily with 400 respondents. It was complemented by in-depth interviews with migrants and key informants including: government officials; humanitarian agencies; NGOs; and activist organizations, who were introduced to offer an analysis of admission systems in both leading countries in Greece and Italy.

The results provided a lot of information on the population composition in both countries, where in 2016 the four most nationalities in Greece accounted for 91% of arrivals, while in Italy the first seven nationalities represented 65%.

One of the defining characteristics of arrivals is the prevalence of the nationalities: the Syrians and the Iraqi Afghans, who are present almost exclusively in Greece and absent in Italy. Nationals from Nigeria, Senegal, Ukraine, Mali, Gambia are represented in Italy and are missing in Greece. Pakistanis are present in large numbers in both Greece and Italy however, it is important to stress that the presence of Pakistanis was far from standard.

During 2018, the asylum service received 2,639 applications from unaccompanied children, where the prevalence of applications received from young boys numbered 2,455 compared to 194 girls. The asylum process at the end of 2018 was carried out in 23 places in Greece. Asylum applications for unaccompanied minors in Italy amounted to 3,676 children in 2018.

Overall, in Greece the asylum service registered 66,969 asylum applications, accounting for 11% of the total number of applications submitted in the EU, making Greece the third largest Member State after Germany (28%) and France (19%).

In 2018, the Syrians were repeatedly the largest group of asylum seekers with 13,390 asylum applications, and applications from 4,834 Turkish nationals were also received. Italy received 7,368 asylum applications for 2018 of which 818 were citizens of Eritrea and 838 asylum seekers from Iraq. 1,589 asylum applications were received from Pakistan.

## Conclusion

On the basis of the UN Charter of Human Rights, international organizations deal with the

minors needs and they emphasize the principle of universality of children's rights. However, the reality in the reception facilities of the host countries is different. Therefore change of this process must be initiated within the UNHCR and the EU agreement.

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**Tab. 1** Participants by survey country, migration wave and country of origin

Country of Birth	Greece			Italy			
	Wave	1	2	Total	1	2	Total
Syria		30.6%	34.6%	32.6%	0.5%	1.5%	1.0%
Nigeria		1.9%	1.3%	1.6%	21.8%	24.5%	23.1%
Gambia		...	...	...	17.8%	13.0%	15.4%
Pakistan		11.3%	11.1%	11.2%	10.4%	3.0%	6.7%
Afghanistan		13.1%	14.4%	13.7%	2.5%		1.2%
Iran		14.4%	11.8%	13.1%	...	...	...
Somalia			0.7%	0.3%	0.5%	2.5%	1.5%
Mali		...	...	...	6.9%	7.5%	7.2%
Eritrea		1.3%		.6%	1.5%	11.0%	6.2%
Iraq		8.8%	7.8%	8.3%	...	...	...
Other		18.8%	18.3%	18.5%	38.1%	37.0%	37.6%
Total		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

**Tab. 2** Arrivals to Europe in 2018, broken down by country of origin. A:Greece, B: Italy

Členenie celkového počtu podľa krajín pôvodu - Grécko		Členenie celkového počtu podľa krajín pôvodu - Taliansko	
Sýria	13 390	Pakistan	7 368
Afganistan	11 926	Nigéria	6 336
Irak	9 731	Bangladéš	5 026
Pakistan	7 743	Senegal	2 867
Turecko	4 834	Ukrajina	2 517
Albánsko	3 319	Mali	2 266
Irán	1 763	Gambia	2 101
Bangladéš	1 552	El Salvador	1 735
Palestína	1 519	Maroco	1 734
Georgia	1 460	Côte d'Ivoire	1 668
		Guinea	1 421
		Ghana	1 171
		Georgia	1 086

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# Perspective of Nurses and Parents Regarding Family Centered Care (FCC) Among Pediatric Patients in Tertiary Care Hospitals, Peshawar

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## Abstract:

**BACKGROUND:** Family-centered care (FFC) is modern and an accepted approach to take care of children and their parents or families in hospital. It is an approach whereby hospital staff (for example, doctors, nurses, technicians etc.) and families work together to take care of ill children.

**AIM OF THE STUDY:** This research activity aims to compare the perspective and perceptions of family-centered care (FCC) by hospital staff (i.e. nurse) and parents of hospitalized children

in 3 tertiary pediatric hospitals of Peshawar, Khyber Pakhtunkhwa, Pakistan.

**METHODS:** A quantitative and cross-sectional research design has been utilized to investigate the perspective and perceptions of family-centered care (FCC). Universal sampling technique has been adopted to select 120 nurses and 170 parents from the population of interest. The information has been collected through questionnaire designed by Finnella Gill and her colleagues in an Australian study to study the perspective and perceptions of family-centered care (FCC). The collected information has been analyzed in tabular form including frequencies, percentage, mean and digraphs.

**RESULTS:** Findings shows that staff mean score is higher for the majority of indicators/statements when compared to parent mean score. Its means that staff has a better perception regarding family-centered care (FCC) in 3 tertiary pediatric hospitals of Peshawar, Khyber Pakhtunkhwa, Pakistan. Efforts are needed to improve the level of satisfaction of parents regarding family-centered care (FCC) in 3 tertiary pediatric hospitals of Peshawar, Khyber Pakhtunkhwa, Pakistan.

### 1.1 Background of the Study

Family is a basic structural and functional unit of any given society. It plays a pivotal role in continuation of generation, taking care of the newborn, their socialization, and provides the new born with socio-economic and psychological care (Macionis, 2011; Kendall, 2007). Family being an important aspect of human life has various impacts on children and it is widely recognized fact that family is pivotal in maximizing a child's potentials (Khan et al., 2017).

Family centered care (FCC) is an eminent dimension of a modern health care system. In words of Los Angeles Children Care Hospital it refers to:

*„a partnership between families and clinicians. It's a collaborative relationship. It helps families set the goals for their child's treatment and recovery“*

Family is the basic entity of a society and family-centered care is considered as an essential component that is globally used for providing care among children and families in both hospital and community settings. Pediatric patient's care and their family involvement can be integrated together to bring improvement in the quality of life among pediatric patients. Study suggested that in European countries like the

United Kingdom and Ireland pediatric patients and their families should be given highest priority during care. Family must be involved during the provision of all the health services provided to their children (Foster, Whitehead and Maybee, 2010). Children are totally dependent on their families for their needs and cannot take their decisions on their own. Family centered care would be an approach towards caring for children and their families within the health care delivery system to ensure planned care around the whole family. By following the same approach both the children and their families could be benefitted and respected by the health services (Stuart and Melling, 2014). As family is an important aspect of the social setup therefore prior decision concerning a child's care parents must be up-to-date. The role of the nurse involves the exchange of complete and unbiased information between the family and health care team (Perry, Hockenberry, Lowdermilk and Wilson, 2013). Family is the crucial and decisive figure in order to maximize the comfort of pediatric patients, therefore, why significance of their involvement must be explored in terms of planning better care for them and their children. Nurses can play a vital role in providing standard care to the children in the presence of their families (Harrison, 2010; Ibilola et al., 2017).



### 1.1.1. Evidence from Statistics: Child Mortality and Morbidity in Pakistan

A report presented by UNICEF in 2018 reveals that Pakistan has the worst newborn mortality rate throughout the world. For instance, 1 out of 22 newborn babies dies in Pakistan. When compared to Japan the risk decreases to 1 out of 111; representing a huge difference. The preeminent factors behind such statistics with regard to Pakistan are poor nutrition; shortage of properly trained medical personnel; lack of health facilities for children; lack of awareness, as well as illiteracy. Further, according to UNICEF Data 25 out of 100 children dies under five years in Pakistan; and, mentioned the same reasons mentioned including poor nutrition; shortage of properly trained medical personnel; lack of health facilities for children; lack of awareness; as well as illiteracy contributing to such high child mortality (UNICEF, 2018). Furthermore, The Nation published an article about child mortality which revealed that about 60% of world's 5.9 million children died before age of five among which the majority belonged to Asian and African states. And, unfortunately, Pakistan is at the top in the list of South Asian states. Prevalence of various diseases e.g. premature birth, pneumonia, diarrhea, malaria and malnutrition are core causes of higher child mortality rates in Pakistan. For instance, pneumonia alone kills approximately 90,000 children in Pakistan annually aging under five (Fatima, 2017).

The UNICEF report elucidates that in 2015 about 5,500,000 children were born in Pakistan which constitutes approximately 14,900 children every day. However, approximately 671 children die every day even before reaching their first month (UNIGME, 2017)

In Pakistan more than 20 million people are under five years age (Pakistan Statistical Year Book 2012). Out of total deaths in a year in Pakistan, almost 50% were reported in under 5 years children. Similarly, out of the total sick persons in Pakistan a large proportion, i.e. about 3/5 are contributed by the children. It has been reported that about 550,000 children under five years die in Pakistan from preventable causes including pneumonia, diarrhea, malnutrition, measles, and malaria. Pakistan has been able to reduce the mortality rate for children by 15% since, 1990, but it was still among the countries with high

mortality in children (Khan, Hussain, Kazmi and Javaid, 2009). Acute respiratory infection in 77 (27%) was the leading disease reported; gastroenteritis was reported in 40 (14%); fever in 53 (19%); helminthes in 10 (4%); skin infections 32 (11%); eye infections 28 (10%); ear infections 9 (3%); 34 (12%) were reported as unknown (Mahmood and Arif, 1997).

### 1.2. Objectives of the Study

To describe the perception of nursing staff towards Family Centered Care for pediatrics in Peshawar

To describe the perception of parents towards Family Centered Care for pediatrics in Peshawar

To compare the perception of staff and parents towards Family Centered Care for pediatrics in Peshawar

### 1.3. Methodology

This study is quantitative and cross sectional in nature and design. This study has been conducted in Tertiary Care Hospitals including KTH, HMC, LRH Peshawar. In the mentioned hospitals the population for the study included nurses and parents accompanying their sick children. The currently admitted patients in pediatric units LRH-80 KTH-50 & HMC 40=170 was the calculated sample size for the current research activity. A total of 120 Nurses were working in the pediatric units of all the three tertiary care hospitals, and were included in the study (LRH-60, KTH-35 and HMC-25). Thereby, it comprised a total of 390 sample size.

Universal sampling (Census) technique has been utilized for selection of nurses and parents accompanying their sick children. Following are the details of inclusion and exclusion criteria of samples“

#### Inclusion Criteria:

Nurses having at least 1 year experience have been selected from Pediatric Units of K.T.H, HMC and L.R.H Peshawar.

#### Exclusion Criteria:

1. Newly appointed Nurses working in Pediatric Units
2. Nurses not willing to participate in the study
3. Nurses working other than pediatric units

Approval has been taken from KMU-ASRB

and the Ethics Board. Permission has been taken from Directors of HMC, KTH, and LRH Peshawar. For this study the data has been collected by an adopted questionnaire (Fenella Gill-Staff Questionnaire) validated with Cronbach's alpha for the reliability for staff 0.71 and parent 0.78, after piloting sample size of 15 nurses and parents reliability for staff nurses 0.73, and for parents 0.72 to know about the perceptions of nurses and parents regarding the family centered care among pediatric patients.

#### 1.4. Data Analysis

**Table 1:** Socio-demographic Information of Nurses

Gender of the Respondents	Frequency	Percentage
Male	34	28.33
Female	86	71.67
Age of the respondents	Frequency	Percentage
25 years or below	15	12.5
26-30 years	66	55
31-45 years	34	28.33
46-50 years	05	4.16
Working with neonates	Frequency	Percent
1-3 years	32	26.7
3-5 years	49	40.8
5-7 years	28	23.3
7 and above years	11	9.2
<b>Total</b>	<b>120</b>	<b>100.0</b>
Current area of practice in the hospital	Frequency	Percent
Pediatric Medicine	44	36.7
Pediatric surgery	13	10.8
Pindaric ICU	22	18.3
Nursery	35	29.2
Pindaric surgery	6	5.0
<b>Total</b>	<b>120</b>	<b>100.0</b>

**Table 1** shows that 34 (28.33%) respondents were male while 86 (71.67%) respondents were female. Further, 15 (12.5%) respondents were aged 25 years or below, 66 (55%) respondents

Data has been analyzed by SPSS Software Version-22 after the collection of complete data. After having proper analysis the data has been presented in the form of graphs, charts, and percentages accordingly. Frequencies and percentages have been calculated for categorical variable and mean and standard deviations have been calculated for continues variable as part of descriptive statistic while the inferential statistic has been used as per requirements.

were 26-30 years old; 34 (28.33%) respondents were 31-45 years old; 5 (4.16%) respondents were 46-50 years old. Additionally, 32 (26.7%) respondents had 1-3 years of working experience with neonates; 49 (40.8%) respondents had 3-5 years of working experience with neonates; 28 (23.3%) respondents had 5-7 years of working experience with neonates; 11 (9.2%) respondents had 7 and or more years of working experience with neonates. Further, 44 (36.7%) respondents were related to pediatric medicine; 13 (10.8%) respondents were related to pediatric surgery; 22 (18.3%) respondents were working in Pindaric ICU. 35 (29.2%) respondents working in nursery whereas 6 (5%) respondents were related to Pindaric surgery.

**Table 2:** Socio-demographic Information of the Parents

Gender of the Respondents	Frequency	Percentage
Male	107	62.94
Female	63	37.06
Age of the respondents	Frequency	Percentage
25 years or below	11	6.47
26-30 years	23	13.52
31-45 years	101	59.11
46-50 years	35	20.58

**Table 2** shows that 107 (62.94%) respondents were male while 63 (37.06%) respondents were female. Further, 11 (6.47%) respondents were aged 25 years or below; 23 (13.52%) respondents were 26-30 years old; 101 (59.11%) respondents were 31-45 years old; 35 (20.58%) respondents were 46-50 years old.

**Table 3:** Comparison of parent and staff perceptions comparison by subscale

<b>Comparison of parent and staff perceptions comparison by subscale</b>		
<b>Sub-scale: Respect</b>	<b>Parents mean</b>	<b>Staff mean</b>
When parents come to the hospital they are made to feel welcome	2.59	3.02
Other members of the child's family are welcome to attend with the child at the hospital <sup>4</sup>	2.59	3.1
Parents are able to be with their child during procedures	3.02	3.27
Parents can question recommendations about their child's treatment	2.47	3.06
Parents are treated like parents (rather than a visitor) when attending the hospital	2.42	2.94
The child's privacy and confidentiality are respected	2.98	3.11
<b>Sub-scale: Collaboration</b>	<b>Parents mean</b>	<b>Staff mean</b>
Parents are prepared for discharge/referral to other community services after their child's discharge	2.68	2.53
Parents are given honest information about their child's care	2.66	3.18
Parents are told whom to call after they get home if they need help or reassurance	2.54	2.82
When decisions are being made about their child's care, parents are included	3.01	3.08
Parents are taught what they need to know about the care their child needs	2.95	3.18
Parents are told the name of the doctor in charge of their child's care	2.61	3.54
Parents can understand the written material that has been given to them	2.43	2.11
The family is included in the care of the child	3.14	2.92
Parents are overwhelmed by the information given to them about their child	1.98	2.26
<b>Sub-scale: Support</b>	<b>Parents mean</b>	<b>Staff mean</b>
Staff are familiar with the child's individual needs	2.81	2.96
Staff listen to parents' concerns	2.52	3.13
Parents see the same staff	2.78	2.35
Staff know who the parents' support people are	2.68	3.16
Staff understand what the parent and their family are going through	3.16	3.32
<b>Note: the mean score is the outcome/mean of 4 level scale ranging from 1-4 i.e. never, sometimes, usually and always.</b>		

The comparative table shows various indicators of FCC and their subscales. The total score was 4 (never, sometimes, usually and always e.g. ranking from 1-4). The first subscale was respect whereby 5 statements were given. First, staff perception scored better (3.02) as compared to parents (2.59) when asked about welcome to the hospital. Second, staff perception scored better (3.14) as compared to parents (2.59) when asked about welcoming other family members to the hospital. Third, staff perception scored better (3.27) as compared to parents (3.02) when asked that parents are able to be with their child during procedures. Fourth, staff perception scored better

(3.06) as compared to parents (2.47) when asked that whether parents can question recommendations about their child's treatment. Fifth, staff perception scored better (2.94) as compared to parents (2.42) when asked that parents are treated like parents (rather than a visitor) when attending the hospital. Sixth, staff perception scored better (3.11) as compared to parents (2.98) that the child's privacy and confidentiality are respected. Thereby, staff mean scores better in each statement about the sub-scale respect.

Further, another sub-scale was collaboration. In this connection, parents mean (e.g. 2.68) was higher as compared to staff mean (2.53) with re-

gard to the statement that parents are prepared for discharge/referral to other community services after their child's discharge. Staff mean (3.18) scored better from parents mean that is 2.66 in answer to the statement that parents are given honest information about their child's care. Again staffs mean is higher (i.e. 2.82) as compared to parents score that is 2.54 for the statement that parents are told whom to call after they get home if they need help or reassurance. Staff mean (3.08) scores higher than parents mean which is 3.01 with regard to the statement that when decisions are being made about their child's care, parents are included. Similarly, staff mean (3.18) scores higher than parents mean which is 2.95 for the statement that parents are taught what they need to know about the care their child needs. Again, staff mean (i.e. 3.54) scores higher than parents mean (2.61) for the statement that parents are told the name of the doctor in charge of their child's care. However, staff mean score (2.11) is low when compared to parents mean score that is 2.43 with regard to the statement that parents can understand the written material that has been given to them. The mean score of staff that is

2.92 score low to parent's mean score that 3.14 for the statement that the family is included in the care of the child. Lastly, staff mean (e.g. 2.26) scores higher to that of parent mean score which is 1.98 with regard to the statement that parents are overwhelmed by the information given to them about their child.

Furthermore, another sub-scale was support. In this context, first, staff mean (2.96) score higher to that of parent mean that is 2.81 with regard to the statement that staff are familiar with the child's individual needs. Second, staff mean (i.e. 3.13) score higher to that of parent mean that is 2.52 with regard to the statement that staff listen to parents' concerns. Third, staff mean score that is 2.35 is low to that of parents mean score (e.g. 2.78) with for the statement that parents see the same staff. Fourth, staff mean (i.e. 3.16) score higher to that of parent mean that is 2.68 with regard to the statement that Staff know who the parents' support people are. Fifth, staff mean (for instance 3.32) score higher to that of parent mean that is 3.16 with regard to the statement that staff understand what the parent and their family are going through.

**Table 4:** Pair T-test for comparing staff and nurses perception towards FCC

Pairs	Mean	Mean Difference	Confidence interval of the difference		T	Df	Sig. (2-tailed)
			Lower	Upper			
Pair 1 When parents come to the hospital they are made to feel welcome	2.82	-.43	-.023	.311	2.179	19	.044
Pair 2 Other members of the child's family are welcome to attend with the child at hospital	2.86	-.55	-.519	-.231	2.854	19	.020
Pair 3 Parents are able to be with their child during procedures	3.14	-.25	-.457	-.042	1.453	19	.163
Pair 4 Parents can question recommendations about their child's treatment	2.77	-.47	.490	.820	-3.559	19	.003

Pair 5 Parents are treated like parents (rather than visitor) when attending at hospital	2.68	-.42	.070	.490	1.000	19	.058
Pair 6 Child's privacy/ confidentiality are respected	3.04	-.13	-.579	-.121	3.199	19	.007
Pair 7 Parents are prepared for discharge/ referral to other community services after the child's discharge	2.60	0.15	.080	.520	1.000	19	.62
Pair 8 Parents are given honest information about their child's care	2.92	-.52	.018	.422	1.453	19	.000
Pair 9 Parents are told whom to call after they get home if they need help or reassurance	2.68	-.28	-.235	.039	5.940	19	.001
Pair 10 When decisions are being made about their child's care, parents are included	3.045	-.07	.083	.170	7.550	19	.000
Pair 11 Parents are taught what they need to know about the care their child needs	3.06	-.13	.008	.392	-4.819	19	.000
Pair 12 Parents are told the name of the doctor in charge of their child's care	3.12	-.93	.080	.520	13.077	19	0.001
Pair 13 Parents can understand the written material that has been given to them	2.27	.32	-.044	.244	2.517	19	.022
Pair 14 The family is included in the care of the child	3.03	.22	-.635	-.165	2.517	19	.048
Pair 15 Parents are overwhelmed by the information given to them about their child	2.12	-.28	-.045	.214	2.517	19	.000
Pair 16 Staff are familiar with the child's individual needs	2.88	-.15	.221	.478	2.179	19	.042
Pair 17 Staff listen to parents' concerns	2.78	-.63	-.055	.155	2.179	19	.013

Pair 18 Parents see the same staff	3.06	.43	-.044	.244	1.453	19	.001
Pair 19 Staff know who the parents' support people are	2.92	-.48	-.519	-.154	2.179	19	.075
Pair 20 Staff understand what the parent and their family are going through	3.24	-.16	-.034	.144	2.517	19	.000

The first pair is parental perception towards FCC while the second pair represents the perception of nurses towards FCC. The mean is the total mean value of the perception of parents as well as nurses while the mean difference represents the difference of means from parents to nurses perception towards FCC. Further, T value represents the value of t-test while the significance is (+-) 0.05. Values in between -0.05 and 0.05 are significant whereas higher or lower than that are insignificant.

### 1.5 Discussion

Family centered care (FCC) is one of the eminent aspects of the modern health care system. Its history traces back to the very beginning of 19th century whereby a first hospital to care exclusively for children was the L'Hopital Des Enfants-Malades was established in Paris. Later in the mid 19th century, the practice of family centered care became quite common in United States. However, the proper practice of modern family centered care introduced in United States whereby children were accompanied by parents in surgeries, stayed with children in hospital as well as other family members visited to them. In the mid 1980s pediatricians, researchers as well as policymakers heard from families that how they care for children at home and what can be the importance of family in child health, diagnosis as well as treatment, and the benefits of joint decision-making. In 1989 the MCHB changed its mission to read:

“Provide and promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families.

With regard to pediatrics care, FCC is pivotal to the modern health care system. Parental and staff (e.g. nurses, doctors and other hospital staff) perception about FCC varies and is an important of topic of debate in current medical sciences. This study focuses on parental and perception of nurses towards FCC in pediatric care centers in Peshawar including Lady Reading Hospital Peshawar, Hayat Abad Medical Complex Peshawar

and Khyber Teaching Hospital Peshawar whereby staff and parents accompanying their admitted children were sampled to know about their perception about FCC.

Findings show that parental and staff perception and perspective about FCC varies in the hospitals of Lady Reading Hospital Peshawar, Hayat Abad Medical Complex Peshawar and Khyber Teaching Hospital Peshawar. In explanation, respondents were questioned through a questionnaire designed by Fenella Gill having three components/scales named as respect, collaboration and support. In terms of respect, there were 6 sub-scales: among these sub-scales the staff mean score was better from the mean score of parents. The subscale were welcoming parents to hospital; welcoming other family members of children to hospital; parents accompanying children during procedures question recommendations about their child's treatment; treating parents like parents; respect for child privacy and confidentiality. In terms of collaboration there were 9 subscales. Among these subscale staff mean score was higher for 6 statements. These statements included giving honest information about their child's care to parents; telling parents whom to call for reassurance; including parents in taking decision regarding child; telling parents about the needs of children; telling parents about the doctor in-charge. Besides, the subscales where parental mean score was higher includes preparing parents for discharge/referral to other community services after their child's discharge; parents being able to understand the written material given to them; inclusion of parents in taking care of children.

In context of support there were five subscales: among these the staff mean score was higher for 4 statements including familiarity of staff with children individual needs; staff listening to parents' concerns. Knowledge of staff about supporting people and realization of staff that what the parent and their family are going through. In addition, for only one statement the parent mean score is high and that is parents seeing the same staff.

## Conclusion

It is evident that staff perception about family centered care (FCC) is much better when compared to perception of parents about family centered care (FCC). Staff perceives that family centered care (FCC) of pediatrics provides better services in terms of support, collaboration and respect. However, much work is needed to satisfy the parents with regard to family centered care (FCC) of pediatric units of sampled hospitals in Peshawar, Pakistan.

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# Effects of Home Environment on Children's Development A Comparative Study

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Original Article

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## Abstract:

Home is the first environment that children encounter which forms the bedrock through which factors that promote their physical, cognitive, social and emotional development are anchored. These promotive factors vary from one home to another. The main objective of carrying out this study was to compare and determine effects of home environment on children's development. For this study, we employed a case-control study design where we had two study groups; Nairobi study group and Bratislava (study control) group. Sample size for the Nairobi study group was 24 respondents while that of Bratislava was 20 respondents. Respondents to this study were par-



ents of young children aged 6-10 years. We used Middle Childhood Home Observation for Measurement of the Environment Inventory (MC-HOME), a standardized questionnaire developed by Prof. Robert Bradley and Prof. Bettye Caldwell to measure home environments of children. We used the Shapiro-Wilk test to determine whether research data were normally distributed and student t for independent sample to compare means of the two study groups. This study found a difference of means between the two study groups ( $p=0.005$ ,  $n=44$ ). The Bratislava study group had a higher mean (mean =42.35, Standard deviation=6.73) compared to the Nairobi study group (Mean =34.21, Standard deviation= 11.27). The two study groups deferred on encouraging maturity, learning materials and opportunity, and physical environment. We also found similarities between the two groups in terms of parental responsibility, setting of emotional climates, family companionship and family integration. We thus, concluded that the four factors that influence development children in home environments namely: proximal processes; Characteristics of the caregiver; Environmental context; time variance from one home to another. This may now explain why developmental trajectories of children are never the same.

## Introduction

Home is the first environment that children encounter which forms the bedrock through which factors that promote their physical, cognitive, social and emotional development are anchored. These promotive factors vary from one home to another. There are some homes that have higher levels of them while others are deficient of them. These promotive factors according to Bronfenbrenner's ecological systems theory are; **i) Proximal processes** i.e. all reciprocal interactions that takes place between children and, people, objects and symbols that surrounds them. **ii) Characteristics of the caregiver**, i.e. do they initiate, sustain or disrupt proximal processes through motivation, temperament or self-control? Are they resourceful to the needs of the developing child such as sharing past experiences, teaching new skills, or providing children with access to social capitals like relevant friends and relatives networks? Do they encourage good behaviors or discourage bad ones? **iii) Environmental context** i.e., physical and social space in which events that directly or indirectly influence children's development takes place such as family and school environments, parents' workplace, and legal space (i.e. bureaucratic procedures and boundaries of national

laws), cultural beliefs and practices. **iv) Time**; influence on the development of the child i.e. during a child's development were reciprocal processes provided in a continuous or discontinuous manner? With what frequency were the proximal processes provided? What events such as parent's death or economic depression happened during a child's development? (Rebecca, Elizabeth, & George, 2016; Edinete & Tudge, 2013; Bronfenbrenner, 1979; Bronfenbrenner, 1994; Robert & Lillian, 2016, Herdics *et al.* 2017).

Homes that are deficient of these four factors that promote development, normally churn out children who are not properly developed in all spheres and in most cases these children do turn out to have behavioral problems (Patricia, *et al.*, 2017; Kalavsky *et al.* 2018) In a longitudinal study of adoptive and biological siblings done by Burt, Mcgue, & Iacono, (2010) found that development of antisocial behavior was more demonstrable in children who were raised in shared environment compared to those who were raised in non-shared environment. Some of the antisocial behavioral children raised in homes deficient of stimulating factors for development are; **Oppositional Defiant Disorder (ODD)** i.e. a disorder characterized by recurrent

pattern of negativistic, defiant disobedient and hostile behaviors displayed by children towards figures of authority such as parents and teachers such as throwing of tantrums and aggression, and **Conduct Disorder** (CD) characterized by behaviors such as aggression, deceitful, destructive behaviors to property, and serious violation of social norms and laws.

The main Objective of this study was to compare and determine effects of home environment on children's development.

## Methods

### 2.1 Study population

This comparative study was done both in Nairobi, Kenya and Bratislava, Slovakia. In Kenya, it was done among residents of Nairobi's South 'B' area and Mukuru Slums. Respondents for this study group were all members of Pentecostal Evangelistic Fellowship of Africa (P.E.F.A) Church south 'B'. Respondents from this population were grouped together to form the Nairobi Study Group (Initialized as NI). In Slovakia, this study was done in two public rehabilitation schools for children with behavioral problems. The two centers were; Diagnostic Center on Slovinska Street Bratislava, and Medical-Educational Sanatorium, Hrdlickova 21, Bratislava. Respondents from these two study centers were joined together to form the Bratislava study control group (Initialized as BA). In both study groups, respondents to this study were parents of young children aged 6-10 years.

### 2.2 Research design

This was a case-control study design that involved comparing two study groups. A total of 44 respondents (24 from Nairobi and 20 from Bratislava) were enrolled into the study using simple random technique.

### 2.3 Data collection

Data for this study was collected using a questionnaire called **Middle Childhood Home Observation for Measurement of the Environment Inventory** (MC-HOME). MC-HOME is a standardized questionnaire developed by Caldwell & Bradley (2018) to measure quality of home environment. It comprises of 59 items grouped into 8 scales namely: Responsivity, En-

couragement of Maturity; Emotional Climate; Learning Materials and Opportunities; Enrichment; Family Companionship; Family Integration; Physical environment. Before administration of the questionnaire, permission was sought from the Bishop of the PEFA church and Directors of Rehabilitation Schools in Slovakia. Before collecting data, written permission to use MC-HOME Inventory was sought and granted by Prof. Robert Bradley of Arizona State University. Informed consent was also obtained from respondents before they were enrolled into this study. A single blind was also used in this study so as to reduce biases associated with data collection using the interview technique. Two sets of standardized questionnaires were given to research assistants. They were asked to administer one set of questionnaires to children and the second one to parents. The one they administered to parents was the MC-HOME Inventory while the second was not. Thus, research assistants did not know who the primary target of the research were.

## Statistical analysis

To conduct data analysis, scores from each MC-HOME Inventory questionnaires were entered in a frequency table. The frequencies were then subjected to the Shapiro-Wilk Test to determine whether they were normally distributed. The Shapiro-Wilk Test results showed that the frequencies were normally distributed. The frequencies were later subjected to student t test for independent samples to test difference of means between the two study groups. A two-sided p value of  $< 0.05$  was set as the threshold for statistical significance. The study data were analyzed using SPSS version 23.

## Results

### 3.1 Difference between the two study groups

We observed an overall difference between the two study groups in terms of their means. Bratislava study group had a higher mean (mean =42.35, Standard deviation=6.73) compared to Nairobi study group (Mean =34.21, Standard deviation= 11.27).

## Discussion

Our overall study results showed there was a difference of means between homes in Nairobi

**Scores per each scale in the MC-HOME Inventory between the two study groups**

		Study Groups		
		Bratislava (BA) N = 20	Nairobi (NI) N = 24	P value
Parental responsivity	Mean ± SD	9.30 ± 1.63	8.75 ± 1.19	
	Minimum	4.00	6.00	0.203
	Median	10.00	9.00	
	Maximum	10.00	10.00	
Encouragement of maturity	Mean ± SD	4.70 ± 1.30	6.00 ± 1.25	
	Minimum	3.00	3.00	<b>0.002</b>
	Median	5.00	6.00	
	Maximum	7.00	7.00	
Emotional climate	Mean ± SD	5.00 ± 1.62	4.33 ± 2.22	
	Minimum	3.00	0.00	0.271
	Median	5.00	4.00	
	Maximum	8.00	8.00	
Learning materials Opportunity	Mean ± SD	5.65 ± 1.27	3.125 ± 2.11	
	Minimum	3.00	0.00	<b>&lt;0.001</b>
	Median	6.00	3.00	
	Maximum	7.00	8.00	
Enrichment	Mean ± SD	5.60 ± 2.04	3.875 ± 2.63	
	Minimum	0.00	1.00	<b>0.021</b>
	Median	6.0000	3.5000	
	Maximum	8.00	9.00	
Family Companionship	Mean ± SD	4.75 ± 1.37	4.08 ± 1.72	
	Minimum	2.00	0.00	0.168
	Median	5.00	4.50	
	Maximum	6.00	6.00	
Family Integration	Mean ± SD	2.15 ± 1.39	2.08 ± 1.86	
	Minimum	0.00	0.00	0.895
	Median	2.00	3.00	
	Maximum	4.00	4.00	
Physical environment	Mean ± SD	5.20 ± 1.96	1.96 ± 2.88	
	Minimum	2.00	0.00	<b>&lt;0.001</b>
	Median	5.50	0.00	
	Maximum	8.00	8.00	
<b>Total</b>	<b>Mean ± SD</b>	<b>42.35 ± 6.73</b>	<b>34.21 ± 11.27</b>	<b>0.005</b>
	<b>Minimum</b>	<b>27.00</b>	<b>16.00</b>	
	<b>Median</b>	<b>43.50</b>	<b>30.50</b>	
	<b>Maximum</b>	<b>54.00</b>	<b>58.00</b>	

(Mean =34.21, Standard deviation= 11.27) and Bratislava (mean =42.35, Standard deviation=6.73). Parents in Bratislava promoted factors that support children's development in their homes than their counterparts in Nairobi. We further examined this difference and found that the two study groups deferred on encouraging maturity, learning materials and opportunity, and physical environment.

Encouraging maturity, the extent to which parents expect their children to demonstrate socially responsible and mature behavior and conform to family rules, is an important refiner of children's behavioral outcome. It shapes their behavior by teaching them what is socially acceptable and unacceptable. There are three ways through which parents can encourage their children to mature: **i)** direct interactions such praising them, or withdrawal of some privileges afforded to them when they fail to follow family rules, **ii)** emotional identification - tend to identify with certain characteristics of their parents such as religious views, ethnicity, social class, personality, talents and interests, etc. **iii)** Sharing stories about family accomplishments propels children to maturity. For example, if a child is told of a story how his/her parents became renowned professors, the child is more likely to be proud of them and would want to follow their footsteps (Kagan, 1999). In our study we observed some differences between the two study groups in terms of encouraging maturity. The Nairobi study group encouraged more their children to be mature and be independent than their counterpart in Bratislava. This observation can be attribute to societal culture in Nairobi that tend to encourage children to leave their parent's homes at an early age (at approximately age 22 years) compared to their counterparts in Bratislava who leave their parent's home later.

The home environment provides children materials and opportunities to learn various skills such as communication, social and emotional skills, motor skills, and cognitive skills like thinking and problems solving, etc. Learning these skills are normally facilitated by proximal processes such as peer relations, plays, and observations (Mattias, 2010; Shahum *et al*, 2017). Learning these skills may be facilitated by materials such as dictionaries, sports and mu-

sical instruments, books and magazines, and trips to museums among many others. In this study we observed statistical difference ( $p<0.001$ ) between the two study groups in terms of how they provided learning materials and opportunities. Parents in the Bratislava study group were more likely to provide their children with materials and opportunities than their counterparts in Nairobi. We attributed this difference lengths of time parents spent on their maternity leaves. We observed that parents in the Bratislava study group had lengthier maternity leaves (approximately 3years) than their counterparts in the Nairobi group who had only 6 months maternity leave. Thus, children in Bratislava enjoyed a prolonged window of opportunity for learning from their parents than respondents in Nairobi. A study done by Liu, Lin, & Chen, (2009) found that children whose parents were not responsive were more likely to develop delinquent behaviors.

Physical environment is a key factor in home environment that aids in stimulating development in children. The nature of a physical environment dictates types of play and activities developing children may engage themselves in. Play has been associated with development of social and psychomotor skills in children. Remmers, *et al.*, (2014). Thus, home environments that are deficient of play space hamper development of children. It denies them opportunities to explore and experiment with their environments. In this study we observed a huge difference in terms of physical environments between the two study groups. Bratislava study group had higher scores (Mean =5.20 Standard deviation =1.96) compared to Nairobi groups (mean = 34.21, standard deviation 11.27). We further observed that houses in Nairobi neither had wall hangings nor were they painted with colors that were friendly to children being dull and monotonous. External playing fields for children were completely not there. Thus, children in Nairobi study groups were forced to either participate in physical activities while in school or not to participate in them at all.

## Conclusions

We observed that home environments for children in Nairobi, Kenya and Bratislava, Slovakia differed in encouraging maturity, learning

materials and opportunity and physical environment. The two home environments also shared some similarities in terms of: parental responsibility; setting of emotional climates; family companionship; family integration. Paternal figures were constantly absent in both home environments. We thus, conclude that the four factors that influence development of children in home environments namely proximal processes, characteristics of the caregiver, environmental context and time varies from one home to another. This may now explain why developmental trajectories of children are never the same

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# Prenatal Palliative Care and Perinatal Hospice – New Challenges in Caring for the Precious Gift of Life in its Fragility

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Original Article

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## Abstract:

Prenatal diagnosis often brings information about serious illness of the child with unfavourable prognosis. Some consider termination of pregnancy; for others termination is unthinkable; others are not sure which path would be a more acceptable or more compassionate choice. In such a situation, to make the final decision, it is important to have a wide range of accurate sources of information at one's hand. Prenatal palliative care and perinatal hospice provide support to those parents who

choose to continue their pregnancy. The approach is based on strict scientific methods joined with thorough health care planning as well as empathy and compassion. The aim of the paper is to point out the innovative possibilities of professional medical assistance to an unborn child diagnosed with serious illness and to its parents, as well as to demonstrate the need for cooperation of health care professionals and helping professions in accompanying such couples.

## Introduction

More and more parents owe the saving of their child's life and health to progress in neonatology. However, the expectations of parents, gynecologists, neonatologists and other specialists in certain situations exceed the limitations of what is possible to achieve while rescuing some children. Even those medical specialities that progress rapidly cannot always maintain the health and life of all children. Although pronouncing a serious diagnosis in the prenatal period, making an unfavorable prognosis, awaiting an expected death during pregnancy, before birth, at birth or even after birth is not too common, nevertheless, it does occur. Even today we are confronted with suffering and death. Medicine as a field offers highly qualified, professional, and comprehensive medical assistance in the form of prenatal palliative care and perinatal hospices. While around the world, there is a growing response to this trend, some countries, including Slovakia, remain passive, despite the theoretical principles and practical steps to the provision of palliative care to children in utero, or newborns with life-threatening and/or life-limiting diseases having been laid out (Fussiova, Bauer 2016).

Every dying is unique and there is no recipe for how it should be handled. The final processing of a loss of a child and the subsequent management of emotions by the family depends on many factors. We believe that accompanying the family through this process is currently a major challenge for healthcare professionals, as well as for other helping professions, and it needs to be addressed. Firstly, we find it instructive to explore how the surrounding countries in the central European region respond to the dissemination of the concept of a perinatal hospice. Secondly, we examine what trends and standards of operating procedures have been laid out in this respect in the world. Additionally, we outline how they have been applied in Slovakia. In this

text, we will emphasize the difference between the classic, established approach to dealing with prenatal diagnoses with life-limiting and/or life-threatening diseases through abortion, and the approach of prenatal palliative care and the perinatal hospice. The aim of this paper is to support the thesis that the perinatal hospice represents a sensitive and especially human approach to the conceived fragile life. Such an approach represents more than just organizational, institutional, and functional change or a specific place of treatment. It is a professional, clinical and interpersonal model of care and service based on a relationship where help consists of the use of strictly scientific medical methods that go hand in hand with healthcare planning, sincere interest, compassion and humanity.

## Prenatal diagnosis and maternofetal therapy

Former Czechoslovakia was one of the countries that were one of the first in Europe to introduce *prenatal genetic diagnosis* into clinical practice in 1971. The integration of prenatal genetic diagnosis and obstetric non-invasive and invasive methods into clinical practice has enabled in-depth and increasingly detailed monitoring of the intrauterine development of the child from its early stages to the moment of birth (Hajek *et al.* 2000). Advanced technologies in the form of modern diagnostic techniques and devices, as well as the improvement and introduction of new laboratory methods, have led to a great development of prenatal diagnosis. Along with this development, the number of detectable genetic defects and diseases has been increasing. There has also been an increase in the number of situations where parents have been faced with information that their child is not and will never be healthy, and/or even more tragically, that their child is suffering from a life-limiting disease (LLD). Life-limiting and/or life-threatening diseases are those that cannot be treated curatively or in which cur-



ative treatment has failed (Kysel, Jasenkova 2018). The overall incidence of life-limiting and/or life-threatening diseases in childhood is 30 cases per 10,000 children in the population. A total of 57,717 children were born in Slovakia in 2016. Of those, 3,390 suffered from a life-limiting and/or life-threatening disease (Trizuljakova, Sitinova 2018).

In the case of testing positive for prenatal diagnosis and the discovery of fetal pathology, it is a common solution to propose to parents a medically indicated termination of pregnancy (Decree of the Ministry of Health No. 74/1986 Coll.). As a rule, women are only offered this one solution, as it is believed that ending a pregnancy is less traumatic for a woman than giving birth to a child that subsequently dies. There is an effort in the world to re-evaluate this solution and substitute it with an alternative offer of tangible assistance (Noia 2019). Taking the alternative route requires shifting focus to maternal-fetal medicine and prenatal palliative care. Additionally, such shift fundamentally changes the goal of prenatal diagnosis: from the decision to terminate the pregnancy prematurely to trying to treat a child causally or symptomatically already in the womb. The present state of the fetus determines the goal of the treatment: whether it is to cure the child; to improve its long-term outlook; to manage the most burdensome symptoms (provide relief); or to provide palliative (prenatal or perinatal) care. The way forward is proving to be possible due to the constant developments in fetal medicine. Thus, both non-invasive pharmacological and surgical therapy of the fetus have become an important option in the present management of several fetal problems (Noia 2019). Trisomy 13 and 18, metabolic diseases, anatomical malformations of the brain and kidneys, congenital developmental heart defects, congenital diaphragmatic hernia constitute some of the most frequent intrauterine pathological conditions of the fetus. Prenatal invasive fetal surgery may also be recommended in strictly selected cases (Ferianec 2014). Although fetal therapy, due to its specific conditions and limitations, constitutes only a small part of the possibilities and postnatal interventions, increasingly more impressive, ambitious and complex procedures are emerging and are thus becoming more accessible (Noia 2019; Dráb *et al.*, 2017;

Ferianec 2014; Tworetzky, Marschall 2003; Noia *et al.*, 1992).

In the case of a child whose death is expected, the parents' original wishes and dreams are collapsing. In Slovakia, of all the deaths of children between 2011 and 2016, 70-75% were unexpected and 30-35% of the deaths were so-called 'expected deaths' (Trizuljaková, Sitinova 2018). However, the parents' hope may be given new meaning and direction, knowing that their child will live a short but dignified life with the utmost professional and comprehensive medical assistance.

### **Prenatal palliative care and perinatal hospice around the world**

*Palliative care* is an approach that improves the quality of life of patients and their families against life-threatening illness by early identification, urgent diagnosis and treatment of pain and other physical, psychosocial, and spiritual problems, and thereby prevents and alleviates suffering. Palliative care includes: healthcare provided by doctors (diagnosis and treatment); nursing care; rehabilitation; psychological care; curative education in children; spiritual care; social care. Palliative care focuses on life, improves the quality of life of the patient and the whole family, and alleviates the process of grief. The basic principles of palliative care in adults and children are the same. However, the decision-making process, treatment, and communication all have their specifics (Kysel, Jasenkova 2018).

*Palliative care for children* is the provision of palliative care to children with life-limiting and/or life-threatening illnesses. It begins on the first day when a serious diagnosis is made and continues regardless of whether the child is being treated by another potentially curative or life-prolonging treatment for life-limiting and/or life-threatening illnesses. It requires a multidisciplinary approach of professionals from various medical and non-medical professions.

*Home palliative care for children born with life-limiting and/or life-threatening disease* fulfils the basic need and desire of children to be and live at home. To illustrate, four children's mobile hospices have been providing home palliative care in Slovakia: *Plamienok* (Little Flame) hospice in Bratislava since 2002; *Svetielko pomoci* (Light of Help) hospice in Košice since 2011,

*Svetielko nádeje* (Light of Hope) hospice in Banská Bystrica since 2015; *Pod krídlami Dominiky* (Under the Wings of Dominika) hospice in Nitra since 2017 (Kysel, Jasenkova 2018).

In 2014, the WHO Global Resolution called on its member states to improve access to palliative care and integrate it into their health systems with an emphasis on primary care and home care. This effort should be fortified by the development and implementation of palliative care guidelines within each country. In Slovakia, experts are currently developing standard operating procedures of palliative care in perinatology within a multidisciplinary team (Chovancova 2019). This initiative's target group consists of the child, its parents, and the family. Health professionals such as obstetricians, midwives, obstetrics and gynecology nurses, neonatologists and pediatric nurses, psychologists, and hospital social workers are the potential everyday beneficiaries of these standard operating procedures. These aim to optimize the quality of life of a child with life-limiting and/or life-threatening illness and to support the family in the decision-making process and enable it to provide care that is in the best interest of the child. Emphasis is placed on: interdisciplinary support of the family; on optimal palliative care for the child; on building a relationship of trust between the family and the medical team. It is difficult to predict the child's clinical condition and quality of life before birth. The child's death may occur during pregnancy, during childbirth, and in the period immediately thereafter. In the case of a stillbirth, standard operating procedures recommend that parents are allowed contact with the child. Touches, as well as farewell rituals, are encouraged, all in an intimate setting and in accordance with the parents' preferences. The implementation of these standards in practice supposes: minimizing of suffering (e.g. pain) and discomfort of children; strengthening of the doctor-patient relationship (parents acting as the child-patient's representatives); reinforcing parents' support of and trust in palliative care; improving awareness and increasing support for health care providers as palliative care providers (Chovancova 2019).

*Prenatal palliative care and perinatal hospices* are a practical response to pathological findings discovered during prenatal examinations of children (literature includes the use of the

terms prenatal and perinatal as synonyms). It focuses on the perinatal period of the child and its parents. According to the WHO, the perinatal period begins upon completion of 22nd gestational week or upon the child achieving the weight of 500 grams until the completion of 7th day after birth (in some countries the limit varies from 22nd to 24th or 28th week of gestation) (Chovancova 2019). It is a compassionate model of support for parents who decide to continue their child's pregnancy after prenatal diagnosis with a life-limiting and/or life-threatening disease. The idea of a 'hospice in the womb of the mother' helps parents to accept any life their child may potentially have. Additionally, it supports them: in childbirth planning; provides emotional support and support in grief; promotes respect for parents' preferences; enables preliminary medical decisions before the baby is born; as well as endorses more traditional hospice and palliative care provided after birth in the institution or at home. Perinatal palliative care, therefore, includes basic care for the newborn such as warmth, comfort and nutrition, and all other means that can improve or make life easier for the child ([www.perinatalhospice.org](http://www.perinatalhospice.org)).

The American gynecologist and obstetrician B.C. Calhoun was among the first to use the term 'perinatal hospice' and became a pioneer in this area (Calhoun *et al.*, 1997). Subsequently, it was two women, a developmental psychologist Deborah Davis (2011) and journalist Amy Kuebelbeck (2003) who brought attention to this topic and the new approach. Kuebelbeck is a freelance journalist and former reporter, editor of *The Associated Press*, and author of the book *The Gift of Time – Continuing Your Pregnancy When Your Baby's Life is Expected to Be Brief*. In this book, she describes her own experience with pregnancy and perinatal loss. She is the initiator and editor of the website, which has continuously provided information on prenatal palliative care from around the world since 2006 ([www.perinatalhospice.org](http://www.perinatalhospice.org)). Today, the site provides information on more than 300 specialized programs running worldwide. These are diverse, varying in the scope of support, assistance and services offered to the parents and the child. Some are established directly in hospitals, integrated into the overall management of a pregnant woman, others are applied in perinatal hospices. There are civic asso-

ciations which operate independently, for example through raising awareness of the subject. Countries, where the program has expanded, include the US (Alabama, Alaska, California, Florida, Illinois, Maryland, Massachusetts, New York, Pennsylvania, Washington, and dozens of other states), Canada, Argentina, Uruguay, Chile, Nicaragua, Australia and New Zealand. In Europe the concept of prenatal palliative care has made its way into practice in the United Kingdom (Scotland, Wales), Germany, Norway, Spain, Hungary and Poland (Korzeniewska-Eksterowicz *et al.*, 2013). Ukraine has also opened its first perinatal hospice by a clinical psychologist and bioethicist sr. Guistina Olha Holubets. She focuses mainly on accompanying parents who have experienced perinatal loss.

Italy is of particular importance in the European context due to the *Center of Prenatal Palliative Care* named after Mother Teresa of Calcutta and the *Perinatal Hospice* at the Faculty of Medicine and Surgery of A. Gemelli at the Sacred Heart University in Rome. Its director, Professor Giuseppe Noia, is also involved in a non-profit organization *Il Cuore in una Goccia* (The Heart in a Drop) aimed at protecting the life and health of the unborn child, with special regard to cases of prenatal pathologies of different natures and severities, and the life and health of the mother. In May 2019, Professor Noia hosted almost four hundred participants at an international conference called *‘Yes to life! Caring for the precious gift of life in its frailness’*. At this event, world experts spoke about the importance of delivering proper and complete information to parents about the real risks of fetal disease as well as about the new approaches to prenatal diseases and the news in fetal medicine (Noia 2019).

### **Prenatal palliative care and perinatal hospices in Czechia and Slovakia**

In the Czech Republic, perinatal hospices have also gained attention. In her research, Katerina Rastislavova points out that insecurity and enormous psychological stress are experienced not only by parents but also by health care professionals who witness a perinatal loss of the child. As a solution, she recommends that health care professionals and cooperating helping professions attend educational courses and training

with a special focus on communication and mourning therapy (Rastislavova 2016). Some of these recommendations have already become a reality. The course *“Care for Parents after Perinatal Loss”* is run under the auspices of the Faculty of Health Care Studies of the University of West Bohemia in Pilsen twice a year, both as a distance and full-time program with all places filled, leaving many applicants on a waiting list each year (Trizuljakova, Sitinova 2018). Additionally, several websites about perinatal hospices have emerged, being mostly informative in nature. The perinatal hospice *Dite v srdci* (Child in the Heart) began to operate in the Ceske Budejovice and Hradec Kralove regions with a team consisting of a gynecologist, psychiatrist, social worker, midwife, doula and a priest. The *Dlouha cesta* (Long Road) Society started a program called *Prazdna kolebka* (Empty Cradle), which aims at assisting parents in dealing with the loss of their child. Moreover, parents who have endured perinatal loss are offered counselling by a Prague mobile hospice *Cesta domu* (A Way Home), originally specialized solely on adult patients, and by a perinatal hospice *Duha* (Rainbow). Concepts, ideas, and the philosophy behind providing prenatal palliative care are spreading around the Czech Republic and reaching the public thanks to education provided by non-profit organizations, as well as through various charity and cultural events ([www.perinatalnihospic](http://www.perinatalnihospic), [www.ditevsrdci](http://www.ditevsrdci)).

In Slovakia, we are not aware of an institution, non-profit organization, or civic association that would specify, disseminate and implement the program and its activities as a systemic provision of prenatal, perinatal palliative care, or would function as a perinatal hospice. Palliative care in our country is usually commenced after the birth of a child and provided in perinatal and neonatological centers. Unsuccessful pregnancies with the expected prenatal and perinatal loss of the child are, nevertheless, a pressing issue.

### **Perinatal loss**

*Perinatal loss* is the loss of a child (fetus, newborn) who dies during the perinatal period. The ability to accept and cope with such loss is determined highly individually and the response remains subjective on the part of each person. It

is the type of loss and experience that can both reinforce interpersonal relationships, but also disrupt them. The effects on for example the physical and psychological balance of parents or family relationships can be detrimental and the event can act as a devastating experience in the lives of those concerned.

Sadness and grief are natural reactions to the loss of a loved one. Parental grief is a deep, cruel, long-lasting and complicated symptom that changes over time. Active, functional, or uncomplicated sadness is a natural, painful, but necessary adaptive response to loss and it includes the emotional, physical, spiritual, social, and intellectual responses of the individual, family, and community. Perinatal loss can turn into dysfunctional sadness at any stage. Research suggests that termination of pregnancy due to a child's congenital developmental defect may subsequently be associated with the woman's psychological distress (Zeanah *et al.*, 1993; Kersting *et al.*, 2004).

Those health professionals who are involved with the effected women and parents the most (especially doctors, nurses, midwives, clinical psychologists, and hospital social workers), play an important role in the adaptation process and in promoting healthy grieving. Helping the parents who grief and addressing their needs enables anticipation and prevention of some of the problems. In their research, Mazuchova and Zaludkova (2014) outline what these needs, expectations, or difficulties may be. They investigated how women who had suffered perinatal loss experienced the provided health care. According to their findings, health care workers focused primarily on the physical aspects and on meeting the mother's physical needs. The women reported unsatisfactory experiences with learning where and to whom they should go for support, with obtaining assistance from a psychologist, with disinterested attitudes of the staff, with no interest in how the family members were dealing with the situation, and with absence of information about the possibility of having a mourning ceremony or burying the child. Health care professionals neither provided nor suggested any commemorative items for the baby, or, at times did not allow such action to be taken. Other findings suggest that parents were not given the opportunity to say goodbye to their child, to see,

touch, or give the child a name. These findings are surprising as the presence of professional psychological and spiritual support according to individual requirements should always be available to these women and families. The authors considered it interesting that several respondents suggested that health professionals should be trained for such situations in advance, for example when obtaining higher education and that they should undergo psychological training for helping women with perinatal loss. The authors considered these suggestions of educational and training activities for health professionals especially well-founded (Mazuchova, Zaludkova 2014).

## Conclusion

When a life-limiting and/or life-threatening disease of a child is discovered during prenatal diagnosis, some parents decide to continue their pregnancy. They should not be left alone under these specific and unique circumstances. The Czech Republic is already responding to their needs through education, courses, lectures, and charity events. In Slovakia, systematic attention to the topic has been lacking and papers on this topic are only sporadically found in the literature. Even so, Slovakia should not be left aside. We are confident that in the beginning very little is needed, a mere first step. The effort can consist of: targeted management of families; of building systematic communication channels; of connecting networks of experienced professionals who are enthusiastic about the concept of perinatal hospices. Such professionals may include geneticists, gynecologists and obstetricians, neonatologists, psychologists, or midwives.

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# Families with a Disabled Child's Perception of Societal Attitudes Towards Them

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Original Article

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## Abstract:

**OBJECTIVE:** The aim of the research was to investigate societal attitudes towards families with disabled children perceived by the parents of children with intellectual disabilities.  
**DESIGN:** Pilot study.

**PARTICIPANTS:** 110 parents, 75 mothers, 35 fathers of children with intellectual and complex disabilities.

**METHODS:** The survey questionnaire contained 30 statements devoted to affective, cognitive and behavioral components of an attitude.

**RESULTS:** In the parents' opinion: society experiences empathy; freedom in contact with these families; accepts them as guest and neighbors; their child's friend; recognizes their

ability to experience a joyful life; happiness; participation in social life; financial independence. can be empathic; recognizes their need of assistance. The only negative attitudes were perceiving families as demanding special privileges, experiencing difficulties in social situations and being easily offended.

**CONCLUSION:** The data shows that the majority of respondents recognize positive social attitudes towards families with disabled children both in affective and cognitive as well as behavioral aspects.

## Introduction

Attitudes play an important role in social life. They significantly determine our response to social stimuli, feelings, as well as thoughts and behavior towards other people or groups (Bohner & Wanke, 2002). Both persons with disabilities and their families are particularly vulnerable to negative social attitudes expressed towards them. This is evidenced by a number of studies conducted in different countries (e.g. Staniland, 2009; Ostrowska, 2015, Barr & Bracchitta, 2012). This phenomenon, due to its severity, importance and negative consequences, has gained significance in the international arena, which has been reflected in a number of international declarations. One of the most influential, the *Convention on the Rights of Persons with Disabilities*, requires in Article 8 that “States that are party to the Convention to raise awareness throughout society regarding persons with disabilities and foster respect for the rights and dignity of disabled persons; combat stereotypes, prejudices and harmful practices relating to them, in all areas of life; and promote awareness of the capabilities and contributions of persons with disabilities” (UN, 2009). While acknowledging the correctness of the declarations made, it should be noted that both actions raising social awareness as well as research should be focused not only on the persons with disabilities, but also their families, as the family as a whole is affected by disability to some degree as well. However, researchers’ attention to the issue of social attitudes has been focused so far mainly on the disabled persons themselves, both in the context of the purpose and the research tools (e.g. Antonak & Livneh, 2000; Findler *et al.*, 2017). The results of the pilot studies presented in this paper attempt to fill this gap aiming at determining how parents of children with

intellectual disabilities perceive the social attitudes expressed towards them by members of society.

## Attitudes towards persons with disabilities in theory

In the most commonly applied structural definition of an attitude, an attitude consists of three different components: affective (feelings manifested in relation to the subject of an attitude in a certain direction: positive - e.g. joy, respect, compassion or negative - e.g. fear or contempt); cognitive (information, knowledge and beliefs about the subject of attitude, suppositions, doubts); ; behavioral (intentional or real behavior towards the object of an attitude, which are a set of dispositions to behave in a specific way) (Smith, 1947). As emphasized by J. Turowski (1993), the above-mentioned components may appear in various proportions and combinations, but there are no attitudes without a cognitive component. Knowledge about the subject of an attitude may take the form of a certain stereotype (e.g. perception of people with disabilities), it may be false or may relate to a fictitious object.

H. Larkowa (1970) made a detailed list of social attitudes towards persons with disabilities distinguishing the following three categories:

- Emotional attitude: positive (kindness, liking), indirect (compassion, pity, indifference) and negative (reluctance to see disability);
- Volitional attitude: positive (acceptance and willingness to maintain contacts), indirect (watching) and negative (avoiding contact);
- Intellectual attitude: positive (recognition, respect), indirect (curiosity, interest), negative (negative assessment of person’s features).

A.E. Sekowski (1994), divided attitudes towards the disabled into positive and negative ones and provided the following variables:



- positive attitudes determined by intellectual predisposition, reflectiveness, high self-esteem;
- Negative attitudes determined by low level of intelligence, low level of creative abilities, impulsiveness.

He believes that most of the manifested positive attitudes towards the disabled are in fact negative ones, often including an element of hostility. This view is confirmed by A. Ostrowska's (2015) research which showed that 60% of respondents exhibit ambivalent attitudes towards persons with disabilities, and another 15% display negative attitudes expressed through avoidance and isolation.

J. Granofsky (1955) presented a more detailed characteristic of positive and negative social attitudes towards the disabled. According to him, both positive and negative attitudes can be described in terms of **1)** criterion for assessing the disabled person; **2)** the cognitive criterion; **3)** the criterion of emotional social interactions. The positive attitudes include: **1)** objective and real assessment of the impact of disability on the psychosocial functioning of a disabled person as well as accepting and respecting her; **2)** positive cognitive attitude assuming that a man, not his disability, is the subject of interest, expressed by knowing his needs and the level of meeting these needs, objectively perceiving his virtues, possibilities and achievements; **3)** positive social behavior expressed by counteracting isolation, maintaining natural and friendly interpersonal contacts as well as integration with the disabled.

The negative social attitudes include such elements as: **1)** feeling of pity or overprotection of the disabled, which are expressed by: underestimating, depreciating, overestimating the impact of disability on the psyche or exaggerating restrictions; **2)** negative cognitive attitude, expressed by: excessive attention to the appearance of the disabled person; attention to disability; overestimation of the "ugliness" of disability; **3)** negative social behavior - expressed by: increasing social distance; lack of acceptance for the participation of these persons in social contacts; a feeling of fear and embarrassment in their presence (Granofsky 1955).

Stigmatization is a highly unfavorable manifestation of negative attitudes towards people with disabilities. According to E. Jackowska

(2009)<sup>1</sup>, the concept of stigmatization refers to: the attitude of social disapproval, the pejorative reception of a specific group of people due to the physical or mental characteristics that distinguish this group from others; the system of values; lifestyle or other attributes. In relation to persons with disabilities, the concept of stigmatization includes several negative, interrelated and overlapping attitudes presented by society such as: distancing (avoiding entering into informal contacts); stereotyping; devaluation (disseminating negative, stereotypical opinions regarding them); delegitimization – (introducing legal restrictions on the possibility of sharing activity in some areas); segregation (blocking access to various forms of activity that are "reserved" for non-disabled). Stigmatization occurs when there are four components that make up this attitude: **1)** isolating what is different, like for example physical disability; labeling the person or people perceived as different; **2)** attributing undesirable characteristics to labeled persons which reflect the stereotypes created earlier; **3)** separating the group of labeled people („them“) from their own group („us“); **4)** labeled persons experience loss of status and discrimination, for example they are deprived of the right to employment, medical care; which entails both economic and social degradation.

A. Czyz (2013) claims that disabled people feel stigmatized by inappropriate social attitudes. This stigmatization results in a limitation or an inability to take up activity; leads to inhibition of self-development activities; hinders the achievement of life goals; blocks participation in cultural life. Disabled people through this social label cannot fully experience and enjoy the world around them. The quality of their lives is also negatively affected by the unsatisfactory quality of social contacts or inability to perform social roles which subsequently leads to low self-esteem, low self-confidence or low self-acceptance.

### **Attitudes towards persons with disabilities in research**

Legal, economic, social and cultural factors have a crucial impact on the way in which society perceives persons with disabilities. In recent years

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<sup>1</sup> after E. Goffman, 1963 and B. G Link, J.C. Phelan (2001) conceptualization of stigma

in Poland, a dynamic transition can be noted from the predomination of the medical paradigm, focusing on individual deficits, to the social and biopsychosocial models focused on the inclusion discourse and functioning of a person with a disability in open society (Barnes & Mercer, 2004; Roulstone & Prideaux, 2012). This shift in paradigm brought about transformations in the area of law, education, economy and culture. It is therefore interesting to see how much it has changed the attitudes of society towards persons with disabilities in Poland. The comparison studies of A. Ostrowska held in 1993 and 2013 confirm their positive, but not complete change. In the study carried out in 1993 only 38% of respondents expressed a positive attitude towards people with disabilities, while in 2013 there was as much as 49% of positive responses. Unfortunately, in addition to a noted increase in empathy, compassion and understanding, there was also a decrease in offering specific help in various situations (Ostrowska, 2015). Moreover, an analysis of current research, including those researching the opinions of persons with disabilities as well, indicates that the main causes of difficulties and limitations they face every day are not only their physical or mental limitations, but also social responses to their disability (I. Wolska-Zogata 2012).

Similar experiences are shared by families with disabled persons. In her research, M. Kowalska - Kantyka (2006) tried to explain the factors determining the relationship between the environment and families raising children with disabilities. She compared the opinions of two cohorts: members of society and the disabled child's parents. Her study showed that most of the parents felt accepted by their immediate family, neighbors and relatives, only in the case of friends were the results unsatisfactory. The parents claimed factors such as unemployment, poverty, an inappropriate healthcare system, and ever-changing legal regulations as clear signs that the social environment is not truly interested in disabled persons. Parents also willingly talked about how they were treated in public places, in institutions, in their place of residence. These experiences cause them to experience bitterness and discouragement, and even lead to avoidance of contact with others. Slightly different conclusions can be drawn from the surveys conducted among society members, which show that society does not perceive them so nega-

tively. The author explains the differences between parents' statements and survey results by the fact that parents most often talked about individual events and problematic situations that stuck in their memories and caused their emotional pain. The author also draws attention to the fact that parents are often hypersensitive and may misread social intentions and therefore avoid social contacts with others. They often prefer to isolate themselves and their children as a precaution, so that they do not experience disappointment or failure in the future.

### **Objectives and hypothesis**

The study presented in this paper investigated society's attitudes towards families with disabled children in the perception of parents of children with intellectual disabilities. The researchers hypothesized that most parents perceive a positive social attitude towards them agreeing with statements describing positive attitudes of society members toward their families and disagreeing with the negative ones both in the affective and cognitive as well as the behavioral aspect of the analyzed attitudes.

## **Method**

### **Participants**

Parents were chosen randomly. A total 110 parents of children with disabilities took part in the survey: 75 were mothers (68%), 35 fathers (32%). All of the children had intellectual disabilities and some complex disabilities combined with autism (11%) or motor disabilities resulting from cerebral palsy and various genetic defects. 101 children attended special schools (76 children aged 3-10; 25 children 11-17 of age) and 9 were adults (age 18-26). The research was carried out in 2018 and 2019 in Poland: two special schools in medium-sized city Radom (N=94=85%) and one in large town Zyrardow (N=12=11%), as well as among 4 (4%) parents with adult children who had already graduated from special schools in Radom.

### **Instruments**

An opinion survey, as one of the direct methods (Antonak & Livneh, 2000), was used to assess the perceived attitudes toward families with disabled children. It was based on the structural

definition of an attitude, J. Granofsky classification (1955) and R.J. Jones (1974) list of social contact types<sup>2</sup>. The survey questionnaire used for the study contained 30 statements. Respondents were asked to express their attitudes by responding to a list of questions about the referent, selecting one of the following responses: I agree, I do not agree, I have no opinion. The statements were devoted to three components:

1) the affective component:

- a. positive: sense of freedom in contact in a public place (7) and among close friends (2); desire to maintain close relationships (21); empathy (24);
- b. negative: pity (16), embarrassment (17), anxiety and fear (19);

2) Cognitive component:

- a. Positive: perceiving abilities: can take part in sport events (8), live among non-disabled (11), earn a living (12); enjoy life (27); be happy (30); contact is helpful to better meaning of life (20); should be more TV programs (22); there is no difference between families (25);
- b. Negative: perceiving lack of abilities: need mainly help (6), experience difficulties in bringing up children (9), come from disadvantaged background (10), want to be privileged (13), are unhappy (15), envy health (18), experience difficulties in social situations (23), are easily offended (28) and demanding (29);

3) Behavioral component:

- a. Positive: accepting the family in different social situations: as neighbor (1), guest at home (4), child's playground friend (3) and classmate (5); partaker in sports competitions for the disabled (26);
- b. Negative: avoidance as social contact is troublesome (14).

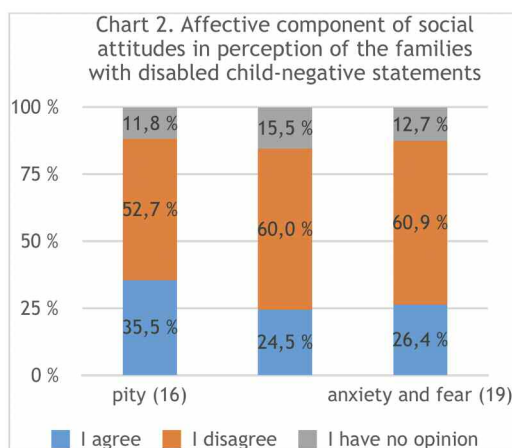
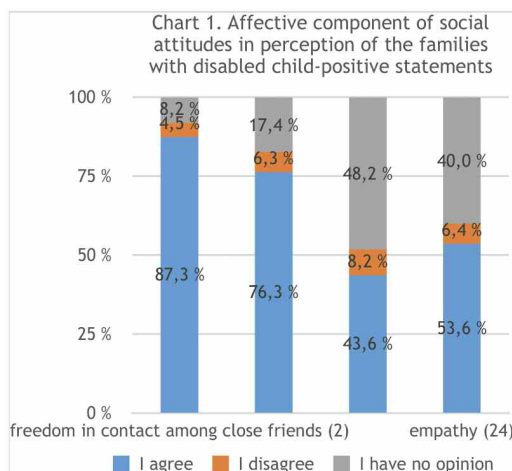
## Results

The research conducted on a group of 110 parents of children with intellectual disabilities and intellectual disability combined with motor

<sup>2</sup> R.J. Jones (1974) distinguished the types of contacts that non-disabled persons would be willing to make with people with disabilities, pointing to situations of acting as a spouse, a club colleague, a colleague, a close friend, a guest at home, a child's friend.

disability or autism concerned their perceptions of societal attitudes towards families with a disabled child. In assessing social attitudes, their three components were taken into account: affective, cognitive and behavioral ones.

Charts 1 and 2 present the parents' opinions on the affective component of societal attitudes towards families with a disabled child. The data shows that the majority of respondents agree that the members of society experience empathy (53.6%) and freedom in contact with these families in certain social situations like being together with close friends (87.3%) and meeting them in a public place (76.3%). Moreover, they do not agree with the experience that society expresses negative feelings such as pity towards them (52.7%), embarrassment (60.0%) or anxiety and fear (60.9%). Only when asked about members of society seeking close relations with families having disabled child, were the respondents'

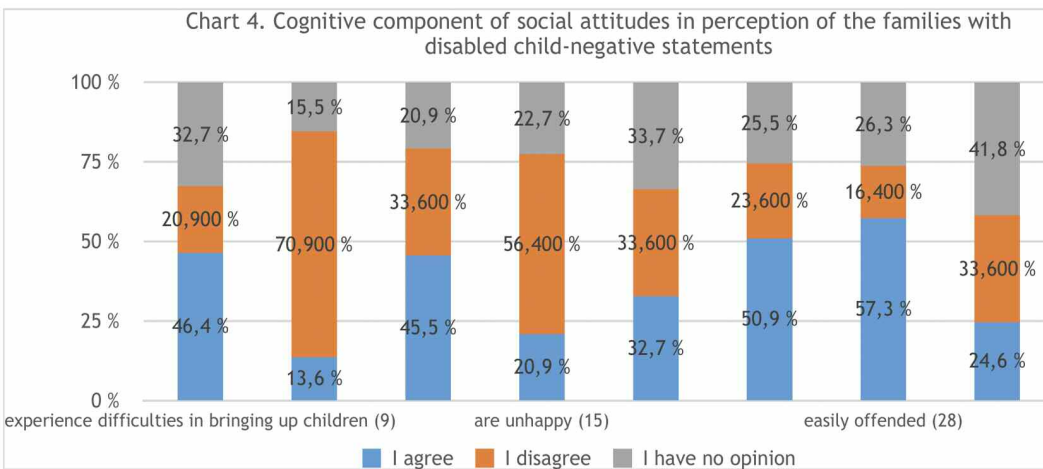
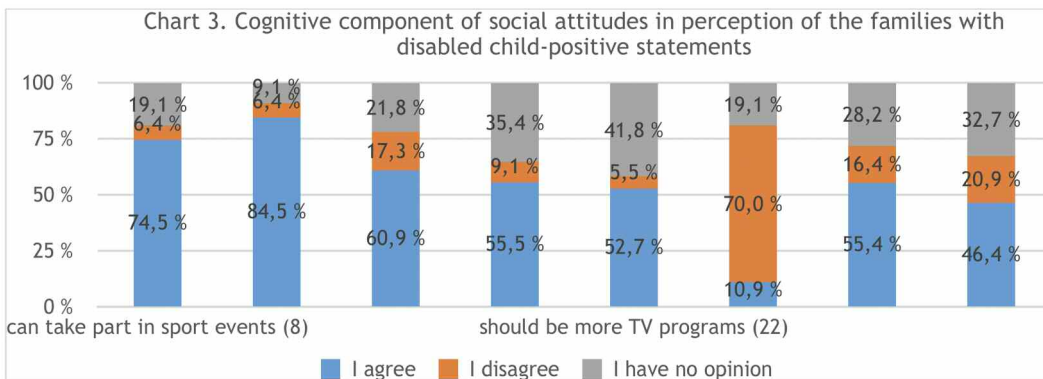


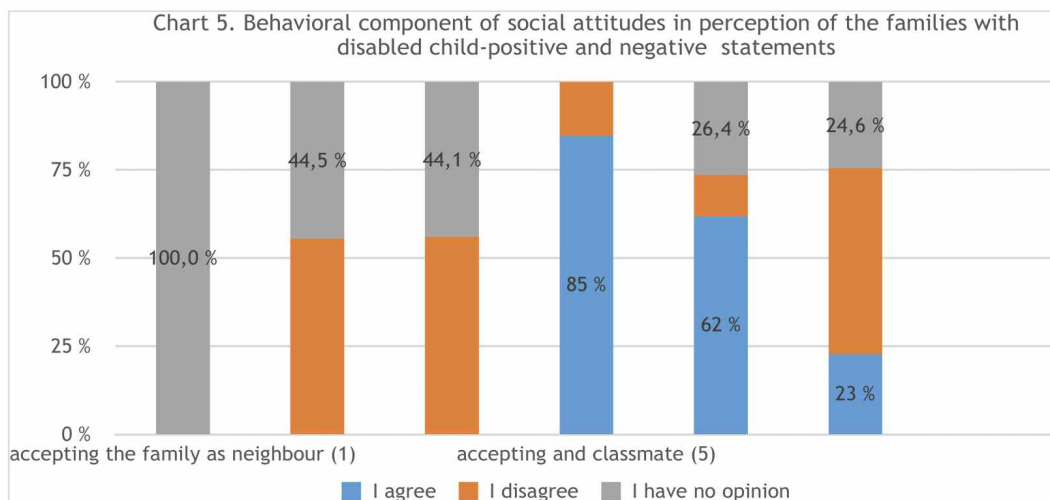
answers polarized, some did not have an opinion (48,2%) and some agreed with this statement (43,6%).

The following charts (3 and 4) present the results of research on the cognitive component of analyzed attitudes. The data shows that the majority of respondents agreed that society assesses the possibilities of families with disabled children to participate in social life in a positive and appropriate way (74,5%; 84,5%), earn their living (60,9%) and experience a joyful life (55,4%). In their opinion, society members (70,0%) do not see much difference between families with and without a disabled person. This does not mean that in their opinion a family with a disabled child does not require social support. On the contrary, most respondents (77,3%) stated that members of society perceive a family with a disabled person as needing assistance. Moreover, in the parents' opinion, the members of the public recognize the need to broadcast more TV programs about families with disabled children (52,7%) in order to broaden their knowledge about their

abilities and needs. The respondents did not agree that society considers families with children with disabilities as coming from a disadvantaged background (70,9%) and as being unhappy (56,4%). However, some respondents pointed to the presence in social consciousness of some stereotypical assumptions, such as the desire of families with a disabled person to have special privileges (45,5%), experiencing difficulties in social situations (50,9%) and being easily offended (57,3%).

Chart 5 presents the results of research on the behavioral component of social attitudes. Their analysis shows that the majority of respondents attribute positive behavior towards their families displayed by the society by accepting them as their neighbor (87,3%), guest at their home (77,3%) as well as their child's playground friend (75,5%) and classmate (70,0%). Moreover, a small majority (52,7%) of respondents disagreed with the statement that society avoids contact with these families due to fear of embarrassment.





## Discussion

The data shows that the majority of respondents recognize positive social attitudes towards families with disabled children in affective, cognitive and behavioral aspects. Society experiences empathy, freedom in contact with these families, is willing to accept them as guests and neighbors, as well as their child's playground friend and classmate. Pity, embarrassment, anxiety and fear are, in their opinion, much less represented in social attitudes. Society adequately and positively assesses the ability of families with disabled children to experience a joyful life, happiness, participation in social life, and financial independence. Members of society do not emphasize these families' otherness, rather they can be empathic and recognize their need of assistance. Despite this, there is, in the parents' opinion, a social need for further awareness of disability issues and its consequences. The only negative attitudes, indicated by the research, were the perception of the families as demanding special privileges, experiencing difficulties in social situations and being easily offended.

This finding agrees with M. Kowalska – Kantyka' (2006) research, which shows that parents experiencing barriers in accessing adequate medical and social assistance, as well as misunderstanding their child's needs and their own fears try to demand their rights and may become hypersensitive, which is perceived by society as a desire to obtain special privileges and that they are easily offended.

## Conclusion

A family with a disabled child is an important part of the social space. As is clear from the comparative research cited in the article, many positive changes in the attitude of society towards these families can be observed. This is the result of the implementation of international conventions and a series of actions aimed at including disabled persons within the social space. Despite recognizing the positive changes, the parents with a disabled person who were surveyed attribute to society certain beliefs that have the character of negative stereotypes. In order to change them in public awareness, a number of long-term actions are required. It is therefore suggested to continue raising social awareness on disability and its effects on family life as well as to share common social activities with the disabled. (Yuker, 1994; Barr, Bracchitta, 2012; Bolt, 2016) This then creates an environment to develop a more realistic view of persons with disabilities and their families' experiences, needs and abilities and consequently more positive attitudes towards them.

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# Out of Home Placed Children in Slovakia

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Original Article

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## Abstract:

One of the saddest features of the 20th and 21st centuries is characterized by the title “The century of abandoned children, the century of living parents orphan children“. Based on the UNICEF estimates, 5 years ago these children amounted to 150 million, according to the latest report their number is inestimable. The primary reason for this situation is the worldwide pandemic of the family disintegration. Slovakia as the post-communist country has been changing its care system from the boarding institutions to today’s centers for child and family.

For forty years, a socialist model of boarding institutional care along the lines of the mission – „to bring up future communist-like young people without being influenced by their bad parents“ was applied in Slovakia. The first open criticisms were heard in 1968; in 1972 the first family-like children’s home was originated in Nove Mesto nad Vahom; in 1976 the Children’s Town in Zlatovce was established. At a turning period in 1989, almost 95% still lived within the boarding system. The average capacity of children’s homes was 204 children...

If we want to assess the system briefly and eloquently, we might say the system of the boarding institutional care organization, characterized particularly by collectivism, strictly organized daily routine and „waiting in a queue“ restricted, or even disabled child’s personality’s healthy development. It disallowed to identify the actual condition of the child’s personality and meet his/her individual formative needs. This system did not provide adequate quality and quantity of stimuli for a child to obtain what is needed for both the present and future.

Children in these institutions have grown up with a small prospect to prove successful in their lives. They were insufficiently prepared for life, they were used to live for today, not to plan anything and just wait passively for the other’s help. As many as 70% of young adults felt problems upon leaving their children’s home, since there was no effective social care system, especially when looking for housing conditions and a job after completion of their institutional care. Due to this fact, most of the fosterlings of substitute care boarding facilities remained dependent on the state’s assistance even after leaving the institution.

**Transformation** – the change process of the entire post-socialist substitute care system, particularly the system of work in institutional care facilities – has taken place in Slovakia on the initiative of the *Society of Friends of Children from Children’s Homes* (Smile As A Gift) since 2000. This largest NGO focusing on the children at risk in Slovakia has performed systematic activities in Slovakia for almost 35 years in order to protect the family. Their vision „...so that every child has a family“ aims to fulfill the basic needs of every child. The main objective is the support of the family and protection of children’s rights by or-

ganizing to advocate and enforce this objective through educational activities, legislative changes, transformation of alternative care system and public care of children and families in crisis, by direct support and assistance to the marginalized groups, to families in crisis or young care leavers. Actively proposing legislation changes, educating professionals working with children and their families, this networking organization is very active in field work and providing practical aid to biological families which are at risk of separation of their children or from which the children have already been separated. In doing so, their work is based on the long-term research which has been performed since 2003.

The primary idea of the transformation of the child care system in Slovakia focuses on a child who, through no fault of his/her own, has lost a possibility and right to grow up in their own family, could be able to return to their family after some time. If the return is not possible, even after making all efforts by the involved team, the priority is to provide living with relatives. If the broader family is dysfunctional or not interested in providing the care, the aim is to find a substitute family for the child. If there is no possible solution in the primary, broader or substitute family, and the child has to be temporarily placed in the institution, the effort is made to enable him/her to live in an environment as much as close to the setting of their biological family. Only in such an environment, a child can have met their needs and exercised their rights. In other words, the transformation is principally aimed at the change of children’s homes from „the last resort to the change resort“.

As mentioned above, the transformation has involved the complex shift of the entire substitute care system. The changes have been made in four principal areas that are interconnected and mutually influencable:

1. Forming an effective and complex prevention system.
2. Development and improvement of field social work with a child and family with the aim to decrease the number of threatened and disintegrated families and reduce the number of children separated from their original families.
3. Development of all forms of substitute family care aimed at increasing the number of children placed in substitute families



4. Transformation of the institutional care system aimed at decreasing the number of children with the ordered institutional and protective care and completion of the consistent transformation of boarding children's homes into the children's homes with autonomous groups.

The transformation of children's homes into the family-like forms of care was completed regarding the fundamental goals in 2006. Since that time we regularly do research of the Family at Risk in Slovakia in cooperation with the St. Elisabeth University showing that on average there are more than 15,000 children growing up out of their families, thereof almost 5,000 in children's homes. The most frequent reason for the children's placement into institutional care is that their parents are not able to address their issues. Only 2% of children are double orphans. Despite this fact, children's homes in Slovakia are filled up to 95% of their capacity. Yet, more than a half (54.7%) of the placed children could come back to their parents, if the family were given appropriate help and support. However, such a scenario is rare, only about 6% of children come back to their parents from a children's home (Mikloskova, 2017). We worked out deep analysis of the situation of children in institutional care in Slovakia to research development of the situation of children at risk in Slovakia in 2006 – 2016. Outcome of this research provided deep insight into the issue of children at risk due to the separation from their families based on socio-economic difficulties in the family and an inadequately established social system insufficiently reflecting the alarming situation of the families at risk in our country. In 40% of all out-of-home placement, the socio-economic situation of the child's family is what matters. In fact, only 5%-6% of children return to their native families. Others remain longtime or permanently separated from their family members and taken out of their natural environment. An alarmingly high proportion is formed by children who, despite emotional ties and parents' interest in caring for their children, cannot grow up in their families due to housing or economic security issues. More than 60% of the taken out children do not have regular contacts with their family, 30% of children have no contact with the family at all. After institutionalized care, in particular aged 18, most of these children (around 80%) return after leaving insti-

tution to their natural environment. Disturbed emotional attachments and disruption of the life continuum of these families, however, have far-reaching consequences (Mikloskova, 2017).

For this reason, since 2007 we have built DORKA Crisis Centers for family restoration in the cooperation of the DeDo Foundation. Our experience with their functioning could get as many as 80% of such families back on their feet. At present, we run 10 crisis centers.

**The research outcomes along with the DORKA Centers** have initiated the idea of the amendment of the Act No. 305/2005 on Child protection and social guardianship which has introduced an extensive reform of the facilities and their transformation into centers for child and family since 1 January 2019. These centers with the help of re-introduced field social work and in-house care systematically work with families focusing on keeping the child in their biological family in order not to be placed in the institutional care.

In prevention of the family disintegration and children's placement into the substitute care system, systematic field social work plays a significant role. The effective work with families at risk is supported by a system of work with threatened families introduced by Smile As A Gift which intensively applies a very effective model of empowering the natural supportive family and community network – Family Group Conferences. It is a system of networking and mobilizing the broader family and the community around the child at risk which autonomously make a plan, accept decisions and take responsibility for problem solving, while the whole process initiating the motivation and potential of the family network is facilitated by qualified coordinators. This way, almost 90% of families have their issues addressed in the circle of the broader family and other persons close to the child. This model has proven that the most effective form of support and help to the threatened families is the mobilization of their own paralyzed potential and initiation of their inner motivation through searching and empowering their strengths and meeting their actual needs.

From time to time, all families have to face challenges, some of them need external help when addressing them. In a traditional family, usually a family member gets some help and support from

the broader family which enables him/her to address the traditional role when providing the care and protection of a child within the family. Over time, a lot of the traditional family roles have been taken over by the society and its social system. When the role of the child protection was taken by the authorities, many of the family members either decided to give up their traditional role in favor of the authority or they found themselves having been excluded from the process, regardless of their concern. Distorting the balance and breaking a family system has had a long-term negative consequences for future generations as well (Miklosko, Bezakova, Herak, 2017).

This phenomenon is apparent in our biggest marginalized population group – the Romani minority. In order to change their situation, two approaches have to be used completely different from those having been applied in Slovakia for the last decades. In the substitute care institutions there are 60% children with Romani ethnicity (Analysis of the situation of children in institutional care in Slovakia, 2017, Children at Risk, 2006-2016) which is, in contradiction with their traditional mentality regarding the separation of the child, unthinkable. The social policy peculiar to the period of communism, which convinced Romani families of the benefits of having the child on the „stay” in the institution, has had enormous consequences. Romani families believed that for their child it was better to grow up in an institution rather than in the family. They gave up their traditional role and today there has grown up the third generation of „institutional fosterlings“ who are uprooted without a clear identity; with all the accompanying phenomena which life with no roots and identity; as well as without relations and family bonds brings. The intensive field social work connected with evangelistic and pastoral activities is very needed and provably efficient in this target group. In this respect, the results of the Greek Catholic Romani Mission are undoubtable.

The execution of the amendment of the Act on Child Protection and Social Guardianship of 2018 and the formation of regionally-available centers for child and family which include in-house, field and residential service for help and support of families in challenging life situations have brought Slovakia to the fore of the EU member countries as to the help of the families at risk.

Finally, we would like to express the belief that a child needs an environment of a complete family including mother and father for their healthy psychosocial development. This is the fundamental condition for meeting their needs and experiencing a safe attachment which is the basis of their future relationships and communication. The stable and favorable family setting can adequately develop the child's personality, enhance their potential and prepare them for future functioning in the broader social context.

Growing up in their own functional family with mother and father is the primary goal we have in our minds. If a child does not have such a possibility, the most appropriate option for him/her is to grow up with their relatives. If even this option is not real for them, the original family can be substituted by surrogate care in the form of adoption or foster care. If neither of these alternatives is possible to accomplish, it is necessary to provide the care of a facility which creates a background resembling their family setting as much as possible.

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