

London School of Hygiene & Tropical medicine

MSc Health Systems Management

**"A comprehensive analysis of early childhood causal factors in
development of Cerebral Palsy in Kosovo. A strategy for prevention"**

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Driton Ukmata

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EXECUTIVE SUMMARY

This research project has been conducted as a part of my MSc studies project report for LSHTM.

The main objective of this research project was the definition of Cerebral Palsy (CP) prevalence in Kosovo and the early childhood causal factors in development of CP.

The research project has been designed as an observational descriptive study and was based on classification and description of the data that have already been collected by Community Workers of Handikos¹.

The study has been based on quantitative and qualitative data observation and as well it involved the focus group discussion with Handikos Community Workers. In addition, several consultations with local neurology specialists have been made throughout the course of the project.

The study was carried out in Prishtina, Kosovo.

For the definition of CP prevalence in Kosovo, the subjects of the study were existing data on 11126 individuals from the Handikos database. For the definition of early childhood causal factors in development of CP altogether 107 diagnosed children with CP were included in study group. This sample was selected among properly registered individuals born from 1999 until end of 2005 (age group 0 to 6).

The main outcomes of the study were:

¹ The local association of people with disabilities in Kosovo

- ❖ estimation of the proportion of CP disability groups within Handikos database - 12.33%,
- ❖ estimation of the prevalence of CP in Kosovo - 4.9 – 6.2 per 1000
- ❖ estimated prevalence of postneonataly acquired CP in Kosovo - 22 %.

The main conclusions of the study are:

- ❖ estimated prevalence of CP in Kosovo is significantly higher than the estimated prevalence of CP in the industrialised world
- ❖ estimated prevalence of CP acquired by post-neonatal casual factors is significantly higher than in the industrialised world.
- ❖ socio-economical status of the families has influence in the prevalence of CP in Kosovo and the infection has been identified as the main post-neonatal casual factor for CP.

Recommendations of the study are that prevention of significant proportion of CP cases could be achieved in the near future; however, this requires serious and continuous mobilisation and engagement of all stakeholders. Due to the specificity of the subject, Handikos should continue to lead this process.

Potential researchers should be encouraged to study this problem in more depth.

Introduction

Cerebral Palsy (CP) is the most common physical disability in childhood². It is a non-progressive disorder caused by lesions or anomalies of the brain arising on the early stages of its development. The main clinical characteristics of CP are disruption of motor functions that are frequently accompanied with mental retardation, epilepsy, visual, speech and hearing problems, etc. The term CP was first introduced into medicine in 1862 by William John Little (Little, 1862), who defined it not as a disease, but rather as a complex motor impairment, that occurs during delivery called “cerebral palsy”. Little described the effect of asphyxia, pregnancy complications, intranatal factors and prematurity on the physical and intellectual development of a child. Furthermore, for many years, CP was called Morbus Little (Morbus from Latin language means disease).

Sigmund Freud (1897 – 1968) was the first to write about CP as a nosographical category, uniting various infantile motor deficits of the brain origin. Unlike Little, when describing the predisposing factors of CP Freud considered antenatal factors as being more important than intranatal antecedents. Since that time there has been no final agreement on the definition and etiology of CP. From the mid-1940s the American Academy of Cerebral Palsy and development medicine and Little club in UK, were among the leaders who moved the concepts and descriptions of CP forward, and caused this condition to become the focus of treatment services, advocacy and research efforts.

According to most of the world researchers who have worked in studying CP the prevalence rate in industrialised world varies from 1.5 to 3 per 1000 born children.

² SCPE, 2000; Stanley et al., 2000; SCPE, 2002; Rosenbaum, 2003

Being involved in the field of disability in Kosovo since more than a decade I could never find a track or evidence of the work done by someone in Kosovo with the purpose of defining if Kosovo fits within this range or not. Knowing the field relatively well, after a lot of years spent in a field working with the people carrying many different disabilities, I decided to move ahead and use the huge quantities of available data with a purpose of giving a minor contribution to this field.

When planning the study, I had a specific interest in analysing early childhood causal factors (post-neonatally) in development of CP, with the purpose of contributing to the prevention strategy.

In summary the known facts that formed the basis of the study were:

- ✓ No one so far has studied this problem in Kosovo, or in the region
- ✓ Relatively high prevalence of CP linked to early childhood causal factor
- ✓ Availability of data
- ✓ Difficult situation of CP cases
- ✓ Inexistence of the prevention strategy.

The **aim** of this study was to compare patterns of this very complex situation at the level of Kosovo with the global ones.

The **main objective** was the definition of CP prevalence in Kosovo and the post-neonatally / early childhood causal factors in development of CP with the aim of creating the possibilities for defining the strategy for preventing/reducing the situation in future.

The study is meant to serve as well as a starting point for future researchers through initiating the discussions on CP within Kosovo.

The specific objectives of the study were:

- ✓ To define the prevalence of different disabilities in Kosovo
- ✓ To specifically define the prevalence of Cerebral Paralysis in Kosovo
- ✓ To define the main early childhood causal factors of CP in Kosovo with the purpose of observing the proportion of post-neonatally acquired CP
- ✓ To define the possibilities of reducing the established risk factors.

The Assumptions of the study were:

- ✓ The prevalence of children with CP in Kosovo is higher than the estimated prevalence of CP in the industrialised world
- ✓ The proportions of post-neonatally acquired CP in Kosovo are higher than in the industrialised world
- ✓ Prevention of significant number of new CP cases can be achieved in Kosovo

The core of the study was the database of Handikos, its detailed observation, consultation with experienced community workers, extraction of needed data and further analysis.

The study was carried out in Prishtina, Kosovo.

Background

❖ Kosovo – general information

Kosovo has an area of 10,908 km² located in southern Balkans. According to the Human Development Report of 2006, the overall population in Kosovo is estimated between 1.9 and 2.1 million people¹; this figure has a variation of 25% depending on the source³. The population of Kosovo has suffered substantially over the past two decades from deep economic, social and political disorders that were the result of deterioration of Yugoslavia.

Kosovo is characterized by a lack of accurate demographic data that is a consequence of its turbulent recent history and the significant population migration and changes that accompanied it. It is estimated that between 350,000 and 400,000 Kosovars live abroad. 42% of the population is urban and the remaining 58% is rural. Kosovo has one of youngest populations in Europe, with 50 per cent under the age of 25 years and 40 per cent under 18 years of age.

In terms of ethnicity, 90% of the people living in Kosovo are Albanians, 8% Serbs and 2% belong to other ethnic groups. The majority of the people are Muslims, although there are a sizable number of Roman Catholics and Orthodox Christians as well.

The reconstruction efforts since the end of the conflict in 1999 have succeeded in putting the Kosovo economy on a growth path.

³ The last census in Kosovo was held in 1981

❖ **Kosovo vital information**

The infant mortality rate (IMR) is estimated between 35 to 49 per 1,000 live births; while under 5 child mortality rate is estimated at 69 per 1000 live births².

The World Bank Kosovo poverty assessment report (2003) states that 37 % of population of Kosovo was estimated to live in poverty. UNDP, human development report on Kosovo – 2006 – states that despite the fact that Kosovo has always been the poorest part of Ex -Yugoslavia making only 67% of average GDP per capita, the Kosovo economy did grow, albeit slowly, from 2000 to 2006. The International Monetary Fund (IMF) estimates the Kosovo GDP for 2006 at 1232 millions of Euros and the GDP per capita at 1232 Euros.

In general there is a lack of knowledge and awareness among communities and families about adequate home care management, child physical and cognitive development and general reproductive health.

❖ **People with disabilities in the world and in Kosovo**

Disability has often been defined as a physical, mental, or psychological condition that limits person's activities. In the past, this was interpreted according to a medical model⁴. This medical model has recently been replaced by the social model of disability⁵, which has been drawn upon by the Theoretical model which is based on International Classification of Functioning, Disability and Health (ICF) by which people are not identified as having disability based upon a medical

⁴ Disability was linked to various medical conditions.

⁵ The model conceptualises disability as arising from the interaction of a person's functional status with the physical, cultural and policy environments.

condition, but rather are classified according to a detailed description of their functioning within various domains.³

Censuses and surveys from around the world take very different approaches to measuring disability. According to one recent review of the literature disability rates ranged from 3.6 to 66 percentⁱⁱⁱ (Brabotte, et al., 2001). UNDP estimates that, in 1990, 5.2% of the world population was experiencing moderate to severe disability.

According to Comprehensive Disability Policy Framework document, issued during 2001 in Kosovo, the number of People with Disabilities in Kosovo has been roughly estimated at 150 000 due to the serious lack of reliable information on the nature and prevalence of disability. According to this document, people with disabilities were rated that they live in circumstances of poverty, isolation and stigma.⁴

❖ **Cerebral Palsy**

In May 1958 in the letter to the Lancet, members of the Little club proposed the following definition for Cerebral Palsy (CP): "a persisting qualitative motor disorder appearing before the age of three years, due to a non-progressive damage of encephalon occurring before the growth of central nervous system is complete" (Mac Keith and Polany 1958). The statement remains as true today as when it was written, and a more recent definition added only minor qualifications: an umbrella term covering the group of non progressive but often changing, motor impairment syndromes secondary to lesions and anomalies of the brain arising in early stages of its development. (Mutch and al.1992)⁵

Today, several classification systems are in use for different types of CP. The most practical classification is the one according to area of brain damage:

- **Spastic CP:** the most common type of CP, accounting to nearly 80 % of all CP cases.
- **Athetoid CP:** affects about 10% of all children with CP
- **Ataxic CP:** affects 5-10% of the children diagnosed with CP
- **Mixed CP:** affects about 10% of children diagnosed with CP

CP has its origin in: genetic and non genetic factors; variables that can be controlled and variables that can not be controlled; single cause and multi cause pathways; hidden and obvious influence; cultural and trans-cultural effects; and most frustratingly the combination of all of the above.⁶

The etiological factors are best defined according to the period of the effect: prenatal, perinatal⁶ and post-neonatally.

The prevalence of CP in the industrialized world is mostly prescribed within the range 1.5 – 3 per 1000 live births

❖ **The significance of the study**

Handikos is a local non governmental organisation that has its roots from the local association of paraplegics and paralysed children that was created in 1983 in Prishtina – Kosovo. This

⁶ Perinatal defines the period occurring around the time of birth (5 months before and 1 month after). The perinatal period commences at 22 completed weeks (154 days) of gestation (the time when birth weight is normally 500 g), and ends seven completed days after birth. (WHO - World Health Organization).

organisation of People with disabilities started the Community Based Programme in Kosovo during 1994 in close collaboration with Handicap International - French non governmental organisation.

This CBR was developed rapidly all over Kosovo and as a result in 1999, after the war in Kosovo the organisation restructured and renamed itself as Handikos. Today Handikos has more than 150 paid community workers who are spread within 25 field offices and receives regular support from huge number of volunteers. I had the chance to collaborate with Handikos community workers on the field all over Kosovo during the period 1994 – 1998, including very remote rural parts. The purpose of our work and home visits we made at that time was to collect information on people with disabilities with the aim of trying to offer support through the community based programme.

My observations from that time were that among variety of pathologies that we were facing, the number of Cerebral Paralysis cases was significant. During the obligatory interviews with the family members, we would very frequently come across CP cases and also receiving information on early childhood disease or situation as a cause of the problem.

Since then I had the desire to study this phenomena in a more depth with a simple purpose of giving my modest contribution in understanding better the causes of this very complex problem.

With my work, I hope I will be able to challenge other researchers, governmental structures, NGO community and donors to make further efforts in studying this problem and draft strategies for prevention.

Literature review

I planned and implemented the literature search in few different phases. During the first phase I reviewed the local professional literature on CP. Being Medical Doctor with a profession, I started the review of general medical study books from Belgrade and Zagreb Universities. I selected these books for review simply because they were the mostly used literature by all local medical students. Unfortunately, I found out that very little space has been given to such huge problem.

Second phase involved general international medical literature search. I was guided by the same principle as with the local medical literature with the purpose of getting the same information as most of the medical professionals working in health centres near the patients and children in risk. The impression I have is that the CP has not been given enough importance and space in this kind of general medical literature.

For example, when going through fifth edition of Clinical Medicine by Kumar & Clark⁷ I noticed that such a comprehensive medical book contains hardly 8 paragraphs on CP and describes the situation as a “disorder apparent at birth or in childhood due to neonatal brain damage” and does not mention the post-neonatal infection at all as a possible cause of a damage.

When going through the tenth edition of “Principles of Internal medicine” of Harrison’s⁸ the CP has been explained as non progressive category of neurologic defect that causes a major disturbance of motor function and has been present since infancy or childhood, the infection has not been mentioned as a possible cause

The third step involved local and international review of professional neurological literature. The same principle has been used as for the general medical literature.

Author B. Radojic⁹, in his Clinical neurology, describes the CP as a situation with disorder or loss of motor functions, which are congenital and appear during the first years of the life. In relation to aetiology, Mr. Radojic classifies the aetiological factors in prenatal (infection diseases of mothers during pregnancy, traumas, intoxications), perinatal (birth traumas, viral infections, icterus, Rh-incompatibility) and post-neonatally aetiological factors (tuberculoses or purulent meningitis, encephalitis and occlusions of brain blood vessels).

Author Z. Levic, in his book “The modern neurology”¹⁰ describes the most common clinical triangle for diagnosis of CP: Spastic paralysis, mental retardation (oligophrenia) and epilepsy.

The fourth step involved local Handikos and UNICEF library search and internet search on specific research work related to CP. During this phase I concentrated on the following:

❖ **Prevalence of disability in the world**

United Nations Disability Statistics Data Base (DISTAT) data show that estimates of disability prevalence range from 0.2% to 20.09% among 55 countries studied. This large variation is mainly due to differences in operational definitions and approaches to measurement and estimation. Surveys using impairment-focused screening questions produced the lowest prevalence rates, ranging from about 0.3% to 5.0% of the general population. In contrast, surveys using activity-focused screening questions yielded the highest prevalence rates, ranging from about 7.1% to 20.9% (Chamie 1989, 1995; WHO 1990)¹¹

The Comprehensive Disability Policy Framework (CDPF) estimated in 2001 the number of PWD's in Kosovo as many as 150,000 or 7.5 % of the population and outlines the possible reasons for serious lack of reliable information on the nature and prevalence of disability in Kosovo:

- There are different definitions of disability
- There is a serious lack on knowledge on different disability types
- Different survey technologies are used to collect information
- There are negative societal attitudes towards people with disabilities
- There are poor service infrastructure for people with disabilities in poor areas and violence levels have impeded the collection of data, affecting the overall picture.

❖ **Prevalence of Cerebral Palsy**

According to Miller & Bachrach¹² of every 2000 infants born, 5 are born with CP. This incidence has remained constant over the last 30 years, despite advances in obstetrical and paediatrician care.

After reviewing different epidemiological studies, Stanley and her co-authors reported the CP prevalence about 2 – 2.5 per 1000 live births.

Collaborators in the SCPE (Surveillance of Cerebral Palsy in Europe) have developed a powerful database for monitoring trends in prevalence of CP in 13 geographically defined populations in Europe⁷. The central database has been developed following agreement on definitions and

⁷ Isere County and Haute Garonne in France, Scotland, Cork and Kerry counties – Eire, Northern Ireland, Goteborg region in Sweden, Northern region UK, Oxford region UK, Tubingen district Germany, Mersey region UK, East Denmark, Viterbo province Italy and Gelderland - Netherlands

classification. The overall prevalence rate for the period 1980 -1990 was *2.08/1000 live births*.

The other specific results of the surveillance are as follows:

- 20.2% of children with CP was found to a severe intellectual deficit and was unable to walk
- Among babies born weighing less than 1500 gr, the rate of CP was 70 times higher compared with those weighing less than 2500 gr or more at birth
- The rate of CP rose during 1970s, but remained constant during the late 1980s

The definition of criteria for defining CP accepted by the Surveillance of Cerebral Palsy in Europe (SCPE, 2000) include following five key elements:

1. group of disorders
2. permanent but not unchanging condition
3. disorder of movement / or posture and of a motor function
4. disorder owing to a non progressive lesion
5. presence of a lesion in the developing or immature brain reaction

Tina Stelmach in her dissertation¹³ gives consideration to a broader group of researchers who studied the prevalence of CP (Perlman,1997; Stanley et al. 2000, Hagberg et al., 2001; Rasenbaum et al., 2002; SCPE, 2002; Suzuki and Ito, 2002). She states the following: At present time, the prevalence of CP over the world is mostly estimated as 1.34 to 3 per 1000 live born children or members of the child population.

❖ **Classification of Cerebral Palsy**

As mentioned in the introduction part, the most common classification of CP in the world literature is classification according to area of brain damage:

- **Spastic Cerebral Palsy**
- **Athetoid Cerebral Palsy**
- **Ataxic Cerebral Palsy**
- **Mixed Cerebral Palsy**

Definitions adopted for European classification of CP (Surveillance of Cerebral Palsy in Europe):

- ***Spastic CP is characterised by at least two of:***
 - Abnormal pattern of posture and/or movement
 - Increased tone (not necessarily constant)
 - Pathological reflexes (increased reflexes: hyperreflexia and /or pyramidal signs e.g. Babinski response).

- ***Spastic CP may be either bilateral or unilateral***
 - Spastic bilateral CP is diagnosed if:
 - Limbs on both sides of the body are involved
 - Spastic unilateral CP is diagnosed if:
 - Limbs on one side of the body are involved

- ***Ataxic CP is characterised by both:***
 - Abnormal pattern of posture and/or movement
 - Loss of orderly muscular coordination so that movements are performed with abnormal force, rhythm and accuracy

- ***Dyskinetic CP is dominated by both:***

Abnormal pattern of posture and/or movement

Involuntary, uncontrolled, recurring occasionally stereotyped movements.

- ***Dyskinetic CP may be either dystonic or choreo-athetotic***

Dystonic CP is dominated by both:

Hypokinesia (reduced activity, i.e. stiff movement)

Hypertonia (tone usually increased)

- ***Choreo-athetotic CP is dominated by both***

Hyperkinesia (increased activity, i.e. stormy movement)

Hypotonia (tone usually decreased)

- **Classification in relation to the severity of CP¹⁴**

- **Mild CP:** presence of neurological signs without functional disability: walking without devices, but displaying abnormal patterns of gross and fine motor movements or limitations in more advanced gross motor skills – i.e. difficulties in jumping or standing on one leg. Classification of R. Palisano et al. (1977)
- **Moderate CP:** obvious motor impairment, i.e. movement disability: walking with assistance, including mobility devices, usage of wheelchair to cover bigger distances, marked limitations or absence of purposeful movements, extremely brisk tendons and periosteal reflexes
- **Severe CP:** Presence of severe motor and intellectual impairment with an inability to sit independently and walk, completely dependent on carers, moving with wheelchair

➤ **Aetiology of cerebral palsy**

- **Aetiological factors during prenatal and perinatal phase:**
 - **Alcohol and poisonous chemicals:** can effect the development of the brain during prenatal phase - Miller & Bachrach
 - **Genetic disorders**
 - **Infections during prenatal and perinatal period** - If infections such as rubella (German Measles), toxoplasmosis (a disease caused by the invasion of parasitic microorganisms), and the virus known as cytomegalovirus are contracted by a women during pregnancy, injury to the fetus's brain may result (Miller & Bachrach)
 - **Low birth weight and preterm birth**
 - Premature infants constitute up to half of the CP population – (Lou 1994)
 - Intrauterine growth restriction (Blair, Stanley, 1993)
 - The risk of CP increases with decreasing gestation at delivery, especially when neonatal survivors are used as the denominator. Whilst the risk is higher in early gestations, most children with CP are born at term. Before 1980 in Western Australia only one tenth of children with CP were born before 32 weeks of gestation; this proportion has risen to one fifth or one quarter." (-Stanley, Blair & Alberman)

- **Malnutrition** – Crawford studied 500 pregnancies and found that the mothers producing low birth weight babies were deficient in 43 of 44 different vitamins, minerals, and fatty acids when compared to mothers producing normal birth weight babies."

- **Oxygen shortage – Asphyxia** - Stanley, Blair & Alberman

- **Thyroid gland** - Abnormal maternal thyroid function in pregnancy may also play a role in CP in developed countries. While it is found in only 1-2 per cent of cases of cerebral palsy, several epidemiological studies have suggested that maternal thyroid disease is a risk factor for both CP (Nelson and Ellenberg 1986, Blair and Stanley 1993a) and neonatal encephalopathy ". Abnormalities of thyroid hormone, particularly deficiency of T4, interfere with neuronal cell differentiation, migration and gene expression (Bernal and Nunez 1995). " - Stanley, Blair & Alberman

- **Additional factors supportive to CP:**
 - multiple pregnancy
 - emergency or elective caesarean section
 - umbilical cord pathology
 - pathological delivery (forceps delivery or vacuum extraction)

- **Aetiological factors during post-neonatal phase:**

Cerebral infection (often meningitis) and **febrile convulsions** (caused by fever, often from malaria) are common causes in infants. Later in childhood, **head injury** appears more frequently as a cause

- **Postneonatally acquired cerebral palsy**

Postneonatally acquired CP accounts for a significant proportion of all CP. In the third world, CP evidences itself postneonatally far more than in the developed countries of the north. It is no less severe and is equally disabling as congenitally acquired CP, with a similar mortality rate to 5 years".

In less developed societies, postneonatally acquired CP is principally due to cerebral infection and febrile convulsions in infancy. As societies develop, causes change and diversify rather than disappear entirely. Infectious causes become less important, and head injury becomes more important. Small numbers also result from causes that might previously have been fatal.

The strong association with social disadvantage make it likely that postneonatally acquired CP is primarily a social disease of poverty and ignorance combining to create barriers to effective parenting." Stanley, Blair & Alberman.

A comparative survey of post-neonatally acquired CP was undertaken in Cape Town, South Africa by Arens LJ & Molteno CD¹⁵. The importance of socio-economic conditions in the causation of post-neonatally acquired CP has not been stressed in previous studies. Three ethnic groups were compared--white, colored (mixed ancestry) and black. The percentage of post-neonatally acquired CP in these groups was 13.2, 24.0 and 36.1 per cent, respectively. These figures can be explained by the differing socio-economic conditions of each group, the white group belonging to the highest socio-economic stratum and the black group to the lowest. The main causes of post-neonatally acquired CP were cerebral infections (particularly meningitis),

cerebral trauma and cerebrovascular accidents. The proportion in each group, the main causal factors, age at onset, types of CP and intellectual status are similar to those of most previous studies.

Little, in his classic paper presented in London in 1862, observed that postneonatal acquisition of CP was 20 times more common than intrapartum acquisition. Thus recent rates in developing countries may be similar to rates of 19th century London and reflect potentially preventable causes that have been largely addressed in developed countries." - Stanley, Blair & Alberman¹⁶

The prevalence of post-neonatal acquired CP in industrialised world is reported at 10% of all other CP types. In developing world the prevalence has been reported up to 40 % of all other CP types.

Ethical considerations

The project was based on the documentary data that were extracted from the questionnaires already collected by Handikos Community Workers. The source of data was the database of Handikos. Names or addresses of the Handikos CP members were not part of the observations.

Individual cases were not observed individually and different groups had enough individuals in order of avoiding possible identification. The results for the groups were described as a whole.

At the end of the study, all photocopied questionnaires will be handed over to Handikos.

In my knowledge the data are not used for another similar study.

I have applied for the London School of Hygiene & Tropical Medicine Ethical Comity clearance during March 2007 and received the clearance on 17th of April after submission of statement from the Handikos related to access to their data.(Appendix 3).

Methods and Results

The study has been designed as a observational descriptive study that is based on classification and description of the data that have been already collected by community workers of Handikos. The study is based on quantitative and qualitative data observation. The study involved as well a focus group discussion with Handikos Community Workers and consultations with local neurology specialists.

During the process of data observation, I was working in a team with one of my colleagues who is a medical doctor and who volunteered to support my research.

The database contains very detailed data that are a great source for variety of different research studies. The questionnaires are made from 4 pages and are divided in the following sections:

- general information on the person with disability and the family
- type of disability / pathology
- medical problems
- mobility
- social life
- recommendations
- proposal for help

- war consequences
- notes

Each section is made of a lot of different questions. For details, please check the Appendix 1 – scanned copy of one of the questionnaire accompanied with scanned copies of medical reports.

The process has started with detailed analysis of the overall Handikos database. During June 2007 the database contained detailed information on 15175 registered individuals. The information are continuously collected by community workers through home visits and with the help of detailed questionnaires.

Due to the problems with database related to classification of individuals within disability groups (for further details please check the DISCUSSION section), we were forced to spend a lot of time in classifying the data with a purpose of getting a clearer picture on the situation and get the proportion of children with cerebral paralysis.

The data on 4050 – 27% individuals contained no information on diagnosis. Based on the time available for this survey we have decided to exclude these uncompleted data from further analysis.

The data on 11126 individuals were used for further analysis.

The first step involved work on classifying the data properly. For this purpose the Microsoft Access database list has been transferred into Microsoft Excel file. The information were checked carefully and based on defined criteria the work on classification has started. The great help in

this process were the consultations with neurology specialists and focus group discussions with Handikos Community Workers.

Despite the classification problems, thanks to such huge availability of data on all the individuals we managed to make ruff classification of existing data according to most important diagnosis and consequences⁸. The Handikos disability groups were rated as mainly physical disabilities requiring daily care. Altogether 31 major disability groups have been identified.

Table 1: Classification of Handikos registered individuals within different disability groups

Diagnosis / Situation / Consequences	Number of registered individuals	Percentage
1 Amputations	889	7.99%
2 Arthrosis	244	2.19%
3 Coxitis	124	1.11%
4 Dystrophy	217	1.95%
5 Encephalopathy & meningitis	530	4.76%
6 Epilepsy	408	3.67%
8 Hemi paresis	510	4.58%
9 Hydrocephalus	97	0.44%
10 Cerebrovascular Insult	1116	10.03%
11 Congenital dislocation of the hip	800	7.19%
13 Syndrome Down	340	3.06%
14 Cerebral Palsy	973	8.75%
15 Morbus Parkinson	83	0.75%
16 Oligophrenia	75	0.67%
17 Osteomyelitis	85	0.76%
18 Plexus-brachialis paresis	117	1.05%
19 Paraplegia and hemiplegia	139	1.25%
20 Congenital abnormalities of the foots	233	2.09%
21 Psychosis	84	0.75%
22 Psycho-motoric retardation	166	1.49%
23 Multiplex sclerosis	59	0.53%
24 Spina bifida	82	0.74%
25 Hearing Disorders	107	0.96%
26 Status post vulnus -	213	1.91%

⁸ The experience from the past on the field of disability, consultations with experienced neurology specialists, focus group discussions with community workers and my medical profession was crucial during the process of classification.

	complications		
27	Status post polio	267	2.40%
28	Spondilitis	76	0.68%
29	Microcephalia	79	0.71%
30	Complicated Fractures	726	6.53%
31	Deformations	65	0.58%
32	Other	2138	19.22%

Total 11126

The data on the diagnosis that are not within the main target groups of Handikos and that contain less than 50 registered individuals are classified under other. The list of diagnosis classified under other can be found as Appendix 2 of this report.

❖ *Focus group discussion with Handikos community workers*

Problems faced during data observation and classification, created the need for more in depth discussion with the main actors in data collection. A focus group discussions was organised with few Handikos Community Workers, Handikos Programme Coordinator and the database clerks. Among the other issues, the discussion was directed in understanding better the registration process in general, the constraints of the Community Workers and the computer registration process at the level of Handikos HQ.

The discussion points can be summarised as follows:

- Accuracy of the anamnesis / history of disability.
- Material support as a motivator for the families of PWD's to request the home visit of Community Workers.
- Problems with registration at the central database.
- Fields for improvement.

The discussion helped a lot in further review of the data and questionnaires

❖ *Prevalence of Cerebral Palsy in Kosovo*

Initially with 973 registered cases, CP was the most represented disability group after cerebrovascular insult within Handikos database (8.75%); however the number was still far from the reality on the field, therefore we were obligated to look at alternative methods in defining this number.

The problems with database, especially with complex situation like CP and the possibilities of registration of the CP cases based on the consequences (hemi-paresis, para-paresis, tetra-paresis, epilepsy, spasticity etc) made us apply the following:

Observe carefully the cases registered within above mentioned disability groups through:

- A. Observing in details the following variables: consequences, localisation of the disability, anamnesis or history of disability, epilepsy, abilities to walk, stand, sit, presence of spasm.
- B. Applying Surveillance of Cerebral Palsy in Europe diagnostic criteria
- C. Applying the diagnostic criteria for cerebral palsy applied by paediatric neurologists in the study of Tiina Stelmach:- Estonia – 2005:
 - i. the presence of permanent motor impairment of a central origin typical for the condition: hemiparesis / hemiplegia, spastic diplegia or tetraplegia, or the ataxic or discinetic subtype of cerebral palsy

- ii. delay in the development of motor milestones and emergence of other motor disturbances from the first months of the years of life
- iii. the failure to develop protective and balance reactions,

D. Observing accompanied impairments, according to the Study on Cerebral Palsy in Western Sweden: Epilepsy, learning disabilities of varying degree and profile, severe visual and hearing impairments¹⁷

We found the following:

- Through analysing first 50 registered individuals within the disability group of different kind of paresis, we saw that 17 cases (34%) should have been registered under CP.
- Through analysing first 50 registered individuals within the disability group of epilepsy cases, we found that 8 cases (16 %) should have been registered under CP
- Through analysing first 50 registered individuals within the disability group of hydrocephalus cases, we found that 6 cases (12%) should have been registered under CP
- From 623 registered cases with Encephalopathy and Meningitis we identified 149 cases that match above criteria and thus classified the children under CP disability group

The updated distributions showed the increase in the estimated proportion of Cerebral Palsy disability group to 1372 individuals making 12.33 % of the overall sample.

Table 2: Distribution of Handikos registered individuals within different disability groups after revision:

	Diagnosis / Situation / Consequences	Number of registered individuals	Percentage
1	Amputations	889	7.99%
2	Arthrosis	244	2.19%
3	Coxitis	124	1.11%
4	Dystrophy	217	1.95%
5	Encephalopathy & meningitis	465	4.18%
6	Epilepsy	343	3.08%
8	Hemi paresis	337	3.03%
9	Hydrocephalus	85	0.76%
10	Cerebrovascular Insult	1116	10.03%
11	Congenital dislocation of the hip	800	7.19%
13	Syndrome Down	340	3.06%
14	Cerebral Palsy	1372	12.33%
15	Morbus Parkinson	83	0.75%
16	Oligophrenia	75	0.67%
17	Osteomyelitis	85	0.76%
18	Plexus-brachialis paresis	117	1.05%
19	Paraplegia and hemiplegia	139	1.25%
20	Congenital abnormalities of the foots	233	2.09%
21	Psychosis	84	0.75%
22	Psycho-motoric retardation	166	1.49%
23	Multiplex sclerosis	59	0.53%
24	Spina bifida	82	0.74%
25	Hearing Disorders	107	0.96%
26	Status post vulnus - complications	213	1.91%
27	Status post polio	267	2.40%
28	Spondilitis	76	0.68%
29	Microcephalia	79	0.71%
30	Complicated Fractures	726	6.53%
31	Deformations	65	0.58%
32	Other	2138	19.22%

Total 11126

In addition to the above mentioned, in calculating the prevalence of CP children we considered as well:

- Lack of data from the enclaves within territories of Kosovo. Approximately 10% of the Kosovo population, mostly Serbs and Roma are living in enclaves where Handikos Community workers have no access

- Based on the world's most recent literature the prevalence of people with disabilities is varying from 1 % to 20 % and for some countries even higher. Referring to the study of Harwood, Sayer and Hirschfeld "Current and future world wide prevalence of dependency, its relationship to total population, and dependency ratios" published in the "Bulletin of the WHO/April 2004, we have found it mostly feasible to determine the Handikos disability groups as disabilities requiring daily care⁹ and used the baseline position of the year 2000 stating that prevalence of disabling conditions requiring daily care is 4 to 5% of the total population. Estimation of UNDP from 1990 that 5.2% of the world population was experiencing moderate to severe disability fits within above range

❖ **Estimated prevalence of disability in Kosovo**

- Estimated population of Kosovo: 2,000,000
- Estimated number of Kosovo population with disabling conditions requiring daily care: 80,000 – 100,000
- Proportion of Cerebral Palsy within Handikos database: 12.33%
- Estimated prevalence of CP in Kosovo: 4.9 – 6.2 per 1000.

⁹ Table with 21 indicators to determine disability severity scores has been used.

❖ **The observation of the main early childhood causal factors of CP in Kosovo with the purpose of observing the proportion of post-neonatally acquired cerebral palsy**

Initially, altogether 107 children with the diagnosis of CP were included in detailed study group. This sample was selected among properly registered individuals born from 1999 until end of 2005 (age group 0 to 6). With the purpose of avoiding bias, the sample consisted of all individuals registered during this period with diagnosis Cerebral Paralysis. The children are from all different municipalities of Kosovo. With the help of Handikos Community Workers we were able to find all detailed questionnaires of selected sample and this was followed by separating and photocopying all of them with the purpose of further observation.

The special importance has been given to the copy of medical report that was accompanying most of the questionnaires.

Two individuals have been excluded from the further review because they were double registered. Further analysis involved 105 individuals.

The principle of defining the *causal factors in development of Cerebral Paralysis* was the creation of Excel tables with specific columns for marking and following different variables.

1. Diagnosis
2. History of disability / anamnesis¹⁰,

¹⁰ Each questionnaire contains a part on the anamnesis of the disease. The community workers are trained well to ask specific questions to the families of People with Disabilities and outline the most important

3. Roots of the disease¹¹
4. Geographic location (urban / rural)
5. Sex
6. Number of members in the family

After observing in details all 105 CP cases from our selected sample we noticed the following:

➤ ***The distribution according to the sex is as follows:***

63 boys and 44 girls with the ratio 1.43:1

➤ ***The distribution according to urban and rural division for CP cases:***

55 are from rural areas and 51 individuals are from urban areas. The ratio 1.08: 1

This distribution does not follow the general Kosovo statistics office estimations: 42% of the population in Kosovo lives in urban areas and the remaining 58% is rural. The ratio 1.38: 1

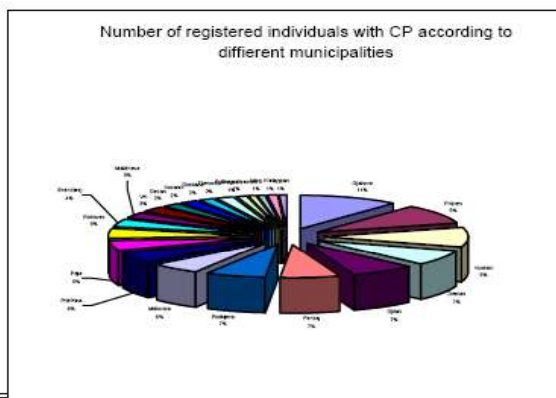
➤ ***Division according to Municipalities***

Table 3: Distribution of CP cases within different municipalities in Kosovo

points. Most of the time, this is supported with a photocopy of medical document issued by specialized hospital or similar

¹¹ Very specific and important question that is answered at the end of the interview by skilled and well experienced Community Workers

Municipality	Number	%
1 Gjakova	12	11.21%
2 Prizren	10	9.35%
3 Vushtrri	10	9.35%
4 Drenas	8	7.48%
5 Gjilan	8	7.48%
6 Ferizaj	7	6.54%
7 Podujeva	7	6.54%
8 Mitrovica	6	5.61%
9 Prishtina	6	5.61%
10 Peja	5	4.67%
11 Rahovec	5	4.67%
12 Skenderaj	4	3.74%
13 Malisheva	3	2.80%
14 Viti	3	2.80%
15 Decan	2	1.87%
16 Kacanik	2	1.87%
17 Dardana	2	1.87%
18 Theranda	2	1.87%
19 Dragash	1	0.93%
20 Fusha e Kosoves	1	0.93%
21 Istog	1	0.93%
22 Klina	1	0.93%
23 Lypjan	1	0.93%
Total	107	



From this table we see that the highest distribution of cases is in the towns of Gjakova and Prizren which are located in western Kosovo and are near each other.

➤ ***Number of members in the family***

The mean for number of family members living together in one family is 9.38 members per family

The mean for number of family members living together in one family in rural areas is 11.3 members per family

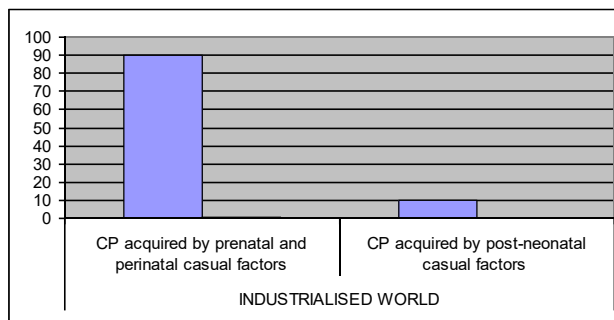
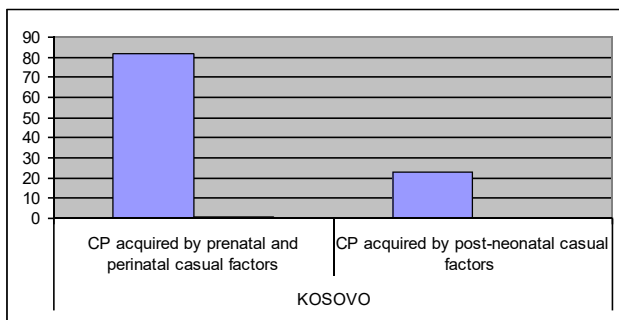
The mean for number of family members living together in one family in urban areas is: 7.3 members per family

➤ ***Casual Factors:***

It was very difficult to make the difference between prenatal and perinatal casual factors from the information that was provided in the questionnaires therefore we decided to group these two groups in one group which has been called CP acquired by prenatal and perinatal casual factors. Postneonatally casual factors were followed based on anamnesis and medical reports attached. Table 3 explains the proportion

Table 4: Proportion of CP cases based on prenatal, perinatal and post-neonatally casual factors

CP acquired by prenatal and perinatal casual factors	CP acquired by post-neonatal casual factors
82	23
78 %	22 %



The casual factors for CP acquired prenately and perinatally follow the common casual factors explained in the world literature: low birth weight and preterm birth, genetic disorders, infections during pregnancy, malnutrition, asphyxia during delivery, difficult birth etc.

Based on the anamnesis the cause for 22 (96%) of post-neonatally acquired CP is infection and high temperature (encephalitis, meningitis and convulsions), only for one case the cause was accident.

For postneonatally acquired CP distribution according to urban and rural division was not following the general ratio for CP cases (1 – urban : 1.38 - rural), instead, the ration was (1 – urban : 1.88 - rural).

The mean for number of the family members living together of individuals with post-neonatal acquired CP is 10.5 members per family

Discussion

❖ Handikos Database

➤ *Problems with classification within different disability groups*

Being away from the developments in Handikos during almost 10 years I had great expectations from its database, but once we started to work on it I understood that unfortunately I was wrong. Despite huge field work in discovering people with disabilities and very detailed questionnaires that have been filled up by very well trained and committed community workers, Handikos failed in classifying the information prior to entering data in the database. The following observations have been made in relation to the above mentioned problems:

- the target group of beneficiaries / members is not defined – due to that the database contains data on very wide span of different diagnosis.

- the data were not classified by professionals prior to be entered into the database

- the workers who entered data in the database had limited medical knowledge so they could not classify information properly
- PWD belonging to the same group are classified into three or more different groups
- Consequences of certain disease or disability are mixed with diagnosis.
- etc

Data on individual's without diagnosis

The data on 4050 – 27% individuals contained no information on diagnosis. The reasons behind this are:

- the lack of professional medical opinions due to the social situation of the families of individuals with disabilities,
- the lack of professional health care centres that could make the proper diagnostic,
- the lack of knowledge and experience of community workers who took data on the field
- problems with data registration in the central database at the level of Handikos headquarters.

➤ ***Classification of registered individuals within disability groups***

During this process, the following observations have been made:

- the wide target group of beneficiaries was influenced by massive humanitarian material support provided by Handikos after the war in Kosovo in 1999. This can be illustrated by registered individuals with diagnosis or situations like: Spondylosis (Spinal Osteoarthritis), scoliosis, patients with cancer, hypertension, minor injuries, wounded etc, etc (for details, please check Appendix 2)

- while collecting data, the community workers, and the families of people with disabilities had their focus on orthopaedic equipment receiving / distribution. Due to that, the focus was on the visible physical impairment therefore in many of the cases consequences were mixed with diagnosis
 - **Example:** male, born in 1974, from a very remote village with, registered with the following diagnosis: hemiparesis.¹²
 - **Explanation:** most probably was in need for crutches and hygienic material, but when we analyse the case further we see that individual has spasm, difficulties in standing, suffers from epilepsy, has difficulties in communication. The anamnesis shows that he had high temperature when he was 16 months old. He has never visited professional health centre and does not possess any kind of medical report.\

- use of very first medical reports explaining the initial problems but not the final situation

¹² 242 cases registered with hemiparesis as diagnosis.

- **Example:** male registered with diagnosis: vulnus explosivum. The person was wounded during the war and as a consequence he had unrecoverable spinal cord injury. The person should have been classified within the disability group of paraplegics.

- mistakes in writing

Other important factors to consider in relation to validity of current data are:

- underreporting,
- cultural perceptions
- the level of development of medical services.

❖ **Discussion on prevalence of CP in Kosovo**

Despite highest infant mortality rate in the region 35 to 49 per 1,000 live births; and very high under 5 child mortality rate estimated at 69 per 1000 live births¹⁸, the prevalence of CP in Kosovo has been estimated between 4.9 – 6.2 per 1000. This estimated prevalence rate has double values compared to industrialised world rate.

The high prevalence of CP in Kosovo can be explained by poverty, underdeveloped medical services (migration of doctors to the towns), the level of education of parents and especially mothers who usually take care of the children, difficult living conditions, the frequent respiratory infections with complications, the presence of tuberculosis due to the patterns of living as defined by HDR -2006, “Families households in Kosovo are traditionally large and sometimes

they consist of more than one nuclear family”¹³, big families with many members living in small houses, home deliveries, pregnant women without antenatal visits.

In addition to the above mentioned factors, we should as well consider the factors that influence the increase of the prevalence of CP in industrialized countries:

- the increasing survival of extremely low birth weight infants, whose excess risk of CP is about 40 fold
- infertility treatments resulting in the increased incidence of multiple births (Winter et al, 2002)

Thanks to international donor support and efforts, the Prishtina hospital has developed very modern neonotological care unit which is equipped with necessary machinery and has professional personnel. Unfortunately the capacities of this unit are limited.

Within our sample, the prevalence of CP is significantly higher in the towns of Gjakova and Prizren which are located in western Kosovo and are near each other. The possible reasons for this high prevalence should be studied further but can also be biased as a result of following:

- The community workers are more motivated and active in discovering new cases
- There was underreporting of CP cases before 1999 in these two municipalities
- There is underreporting in the other municipalities
- The level of destruction during the war was high in these two municipalities, especially in Gjakova. And this fact raises a lot of other questions and variables that can be subject of another study.

¹³ Family households consist of people who live and eat together and share their income.

- The municipalities are far from Prishtina neonatological centre¹⁴

The number of family members of CP children living in the same family is significantly high, in average 9.38 / rural 11.3 / urban 7.3. According to the HDR report of 2006, the family households in Kosovo are traditionally large with the families in rural areas being traditionally larger, averaging 6.4 members and families in town being smaller.

❖ Discussion on postneonatally acquired CP in Kosovo

The observation of the estimated prevalence of postneonatally acquired CP in Kosovo has shown that 22% of CP cases from our sample have acquired CP during their early childhood. This prevalence rate is high compared to prevalence rates from the industrialised world that range from 1 to maximum 10%, depending on the author. Due to these low rates, in industrialised world the postneonatally acquired CP is given a very little space in research work.

The mean for number of the family members living together for post-neonatally acquired CP is higher than the mean for the number of family members for CP cases in general.

65% of these children live in rural areas, this is higher than the ratio for CP cases in general

The high rate of postneonatally acquired CP in Kosovo, creates additional concerns when we take into consideration the very high infant mortality rates and under five child mortality rates in Kosovo.

¹⁴ The hospitals and family health center networks of Prizren and Gjakova are relatively well developed.

All these facts, direct our attention to the possible causes for this problem. According to my experience and based on the discussion with colleagues from the humanitarian sector in Kosovo I have outlined the following possible factors for this huge problem:

- The poverty of families living in remote rural areas. (World Bank estimates that 37% of the families in Kosovo live in poverty, still about 15 % of population live below the extreme (food) poverty line of Euro 0.93 per equivalent adult per day.)¹⁹
- The low level of education
- Traditional beliefs
- One decade of parallel system during 1990s¹⁵
- The migration of medical and other professionals after 1999 from rural areas towards urban areas.
- Underdeveloped family health services in rural areas.
- Lack of expertise of family doctors in recognising risks of brain damage at early stages.
- Lack of professional neurology centre at the level of Kosovo.
- Underdeveloped infrastructure in Kosovo

In long term, the influence of all above mentioned factors will be reduced or eradicated with efforts for development of all sectors of life in Kosovo. In short term, there is an urgent need to face the problem and initiate discussions at all levels with the purpose of defining strategies for prevention at national level.

¹⁵ During 90s after suppression of the Kosovo autonomy by the Republic of Serbia, Kosovars organised a parallel system of functioning involving all aspects of life. This arrangement continued until NATO war in Kosovo in 1999.

Conclusions and Recommendations

❖ Conclusions:

Most of the study objectives have been met. The research process was smooth and productive. The time available for the study did not allow the necessary time for raising funds and preparing the information booklet for young parents, health workers and community workers.

Unfortunately, most of the assumptions I made at the beginning of this study and had in mind since a long time have been enforced. I hope that outcomes of this study will trigger further research work and prevention strategies.

The main outcomes of the study suggest the following:

- Database of Handikos contains very valuable information for the situation of PWD's in Kosovo and should be used by researches in future work.
- The estimated prevalence of CP in Kosovo is significantly higher than the estimated prevalence of CP in the industrialised world
- The prevalence of CP has been estimated to be higher in western parts of Kosovo
- The number of family members living together of CP children is significantly higher than the estimated averages for Kosovo.
- The estimated prevalence of CP acquired by post-neonatal casual factors is higher than the estimated prevalence in industrialised world

- The estimated prevalence of CP acquired by post-neonatal casual factors is higher within the children coming from rural areas of Kosovo.
- The infections (encephalitis, meningitis and convulsions) have been identified as the main post-neonatal casual factor for CP in Kosovo.
- The number of members of families and the socio-economical status of the families has influence in the prevalence of CP in Kosovo
- The reduction in the prevalence of CP in Kosovo is achievable.
- The reduction in the prevalence of post-neonatal acquired CP in Kosovo is achievable

❖ **Recommendations:**

- Handikos database is a very valuable resource of information. The recommendation is to engage a group of specialists to work on defining criteria for disability groups of Handikos and for initiating the activities for modifying the database accordingly.
- Handikos should organise a round table discussion, on the results of this survey, involving all important stakeholders. (parents of children with CP, CP individuals themselves, representatives of other Handikos disability groups, Ministry of Health, Ministry of Social Welfare, Ministry of Education, specialists from the Neurology clinic in Prishtina, International donor agencies, etc)

- The policy makers should be informed on the outcomes of this study. The recommendations resulting from the Handikos round table discussion should support strategy for prevention
- The efforts should be made in identifying all individuals with CP in Kosovo. The ruff estimations are that the database of Handikos contains data only on 1/4th of this group.
- Analyse the reasons behind the higher prevalence of CP in the towns of Gjakova and Prizren which are located in western Kosovo.
- Continue research further for CP registered members with the purpose of defining the distribution of different types of CP.
- The research activities involving Handikos database should be continued further, not only involving individuals with CP, but also other disability groups.
- The family health centres all over Kosovo should prioritise the care for pregnant mothers and infants.
- Handikos and Ministry of Health should be engaged together in production and distribution of information booklet for young parents and professionals and use of TV and other media for advertising on prevention of this problem. The target group for these campaigns should be the families of CP individuals, health workers, social workers and community workers.

- The time available for the study did not allow observing the current care and support for children and families of children with CP. This process is very important to be accomplished while defining the general strategies for CP.

Appendixes

APPENDIX 1 – Scanned copy of randomly selected Handikos questionnaire

APPENDIX 2 – List of diagnosis classified under “other”

APPENDIX 3 – Statement of Handikos on free access to their data

GLOSARY

CBR - Community Based Programme

CDPF – Comprehensive Disability Policy Framework – Kosovo

CP – Cerebral Palsy

DISTAT – United Nations Disability Statistics Data Base

HANDIKOS – The local association of people with disabilities in Kosovo

HDR – Human Development Report – Kosovo 2006

ICFDH – International Classification of Functioning, Disability and Health

IMF – International Monetary Fund

IMR – Infant Mortality Rate

LSHTM – London School of Hygiene and Tropical Medicine

PWD – People with disabilities

SCPE (Surveillance of Cerebral Palsy in Europe)

UNDP – United Nations Development Fund

WHO – World Health Organisation

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I have to congratulate all Handikos members for the great work done during more than a last decade and at the same time to express my gratitude for them for allowing me the access to these very valuable and delicate information. I would especially like to thank Mr. Halit Ferizi, the president of Handikos, who has been the inspiration for all my efforts and contributions in the field of humanitarian work since 1994.

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At the end I have to thank my wife Besnike who supported me a lot in accomplishing this work. Her support and encouragements were crucial during the frequent moments of difficulties with the study.

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