

## CHILD- AND FAMILY-CENTERED CARE IN THE TREATMENT OF CHILDREN - KNOWLEDGE, ATTITUDES, PRACTICE

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### SUMMARY

Despite the advances in medical technology, health care improvements have not always been accompanied by commensurate attention to the child's well-being. Psychological and emotional status of children during hospital treatment is often underestimated. Namely, certain kind of institutional negligence is frequently present in everyday practice in children's institutions.

Many hospitals in Bosnia and Herzegovina (B&H) have become child-friendly during the implementation of the Project on Child-Friendly Hospitals supported by UNICEF and WHO. Apart from the introduction of child friendly environment, staff in hospitals was trained to provide a holistic approach. The program was closely linked to the Baby Friendly Hospital Initiative that supported breastfeeding.

A few years thereafter, our focus is still on the physical treatment of sick children, whereas the attention to their anxieties, fears and suffering has failed.

A more serious approach to this problem is needed and should begin at an educational level in medical school programs. Accordingly, our philosophy (mission) should change from a mechanical (techno-) medicine to holistic medicine.

**Key words:** Child-Friendly Hospital Initiative (CFHI) - rights of hospitalized children - medical humanity training

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### Introduction

Technological and scientific advances in medicine have led to measurable improvements in the treatment and care of sick children. After such success, medical workers' reception is often lulled for the 'immeasurable' but equally important aspect in the treatment of disease, i.e. psychological aspect of technological progress.

Clinical medicine tends to put the scientific focus strictly on bodily systems, expressed in exact mathematical calculations of the child's physiological needs, while the child's psychological integrity, either present or future, is ignored. During hospital treatment many children are exposed to psychological harm that is largely avoidable, and which has or may have permanent consequences in the child's life.

This kind of mental and physical "abuse at the hospital," has been observed as a separate nosological entity since the end of the 19<sup>th</sup> century in children treated adequately by all medical protocols. Despite up-to-date medicine, for "unknown" reasons, healing has failed. The children progressed poorly, falling behind in growth, and some of them died. Studies have shown that the separation of the child from his/her mother was the reason for treatment failure. It is clear that the symbiotic mother-child relationship is a part of the normal biologic developmental process and that the "sanctity" of this communion should not be disturbed. This should apply without exception, even when giving medication or performing surgery ([www.de.wikipedia.org/hospitalisms](http://www.de.wikipedia.org/hospitalisms)).

The child's medical needs often appear opposite to their actual needs: in their physically most difficult moments (such as illness), there is a great need for love and support by the closest and well known persons (mother and/or father). By the end of the 19<sup>th</sup> century the word *hospitalism* was coined, which was specified and explained in the works of Rene A. Spitz (Spitz RA, 1946). In so-called "Western medicine", there is a well-established practice in adult psychiatric services that pays special attention to the amount of time patients spent in hospitals during their childhood. The amount of time spent in hospitals is a risk factor the development of mental disorders later in life (Nagera 1978)!

### Institutional aggression against a child

Ignoring the child's psychological needs during their stay in the hospital is particularly emphasized in developing and low income countries. The focus of medical praxis is on diagnosis and treatment, whereas psychological needs are treated as "luxury fad" of the child and parents. Therefore, during the hospital stay, a child is exposed to parallel types of treatment: negligence of the child's emotional life, and sometimes very aggressive medical treatment without any psychological support by staff (Southall 2000).

Sometimes this is done unknowingly, but examples of conventional aggression against a child can be easily found in daily practice:

- Separation of a child from his or her parent(s) (during the child's hardest moment).

- Separation from parents and loneliness during invasive procedures (child is unprotected and vulnerable).
- The absence of adequate analgesia (physician has no time for the procedure, does not care, or acts believes what's done fastest is best).
- The lack of a complete and adequate explanation to the child and parents about the disease and its treatment.
- Use of rude methods of binding with rough supporters during the invasive procedures, whether painful or not for the child (more frequent in earlier practice than today).
- Unjudicious use of intramuscular injections, and sometimes repetitive and painful (no analgesia) attempts to access venous lines.

### Rights of Children

The UN adopted the Convention on the Rights of the Child in 1989. In September 1990, "World Declaration on the Survival, Protection and Development of Children" was adopted as well as a plan for implementation of the Convention. The rights of children have been given high priority. In a way, it was correction of centuries-old injustice against children: they were considered unequal members of society until the age of full maturity.

Due to their sensitivity and vulnerability, children around the world have been abused in various ways through the centuries, and defense from the abuse was a "private" issue. Now the actions of child protection from all kinds of humiliation are at the forefront of all declarations signed by any country at the moment of their reception to the family of officially recognized countries.

Bosnia and Herzegovina ratified the Declaration on the Rights of the Child in 1993. After the 1992-1995 war, it has become clear that children are the innocent victims of "adult games" and there is a special sensibility to implement the Convention, as well as real efforts to improve the position of children in society (O'Flaherty 1998).

### Protection and support of children

The worldwide action "Baby Friendly Hospital" and thereafter „Child Friendly Hospital Initiative“ began after 1991, inspired by UNICEF and WHO. In B&H, the Baby Friendly Hospital Initiative started in 1995. Out of total of 40 maternity wards in B&H, 22 wards (55%) were certified as Baby Friendly (DSG). It has significantly improved the care of mothers and newborns on maternity wards (www.childinfo.org. 2013)

Some studies taken during the war showed a catastrophic decline in breastfeeding rate of infants in the first 4-6 months of life and unjustified increase in

the use of substitute milk in infant feeding (formula) (Ademović 1998).

After the implementation of Baby Friendly Hospital action, there has been a gradual increase in breastfeeding rate of infants and return to breastfeeding culture. Investigation of multiple health indicators (MICS) in 2012 in B&H showed an increase in rates of exclusive breastfeeding up to 6 months old infants from 5% to an average 19% (www.childinfo.org/mics4). That is one of the results of mothers' rooming-in after birth, as well as of the positive attitude of staff towards breastfeeding mothers. The introduction of "training program" for pregnant women on the maternity wards and active preparation for childbirth enhances and enriches one of the most stressful yet most beautiful events in a woman's life: the birth of a new life.

There is also a possibility of the father's birth attendance, which demonstrates how care and attention is being slowly focused to include the whole family. Thus father starts to participate early in the child's care, which is a big change in the attitude in this region, since, until recently, caring for a newborn has just been "mother's problem."

One of our studies on breastfeeding practice in Herzegovina showed very little support for breastfeeding from husbands. The gap in prenatal care could be filled only with broad and systematic actions of all health care workers (Šimić 2004).

Child Friendly Hospital Initiative (CFHI) was launched as a project by WHO and UNICEF in Bosnia and Herzegovina from 1998 to 2004 and was implemented by HealthNet International Organization (Dutch International Organization). 13 hospitals in B&H became child friendly during this period (Sarajevo, Mostar, Banja Luka, Tuzla, Bihac, Prijedor, Brcko, Zenica, Livno and Trebinje) (Mladina 2004).

Medical staff underwent a process of training in developmental psychology, communication skills, a holistic approach to child care, knowledge and skills in the treatment of pain, and dealing with families in the case of a child's death. Hospitals hours have been made to accommodate the long daily schedule of parents. Parents can participate in the in hospital care of their child. There is also an opportunity for volunteers to get involved in various capacities. All these goals have propelled the level of health care of children throughout the country a step forward. After the war trauma in which the child was suffering collateral damage, a very practical attempt was to reduce further suffering of children in health institutions (Mladina 2004).

The last two decades have seen an increase in the involvement of psychologists in pediatric health care. It was realized that the neglect of children's emotions during treatment leads to psychological trauma (often with a lifelong impact) and that all the success achieved in the field of somatic healing can be devalued through mistreatment by medical staff. Most European countries

have already made transformations in the hospitalization of children in terms of the tenets of the child friendly hospital.

The importance of changing the focus from "the disease of the body," to the "whole person," is perhaps most significantly expressed in the pediatric medical profession. There is no medical discipline which so widely affects the health of one segment of the population such as pediatrics. We are not only concerned with clinical pediatrics, but social pediatrics as well. Pediatrics considers the whole body (not just one organ) and wide range of ages (newborns, infants, toddlers, school children, adolescents to 18 years).

Pediatrics is concerned not only with clinical research and treatment, but also with the societal aspects of this population (kindergartens, schools, prophylaxis of infectious diseases, children with special needs). Pediatrics embraces a wide array of activities as no other medical field does, which is why the training of pediatricians should be multidimensional, including a humanistic professional selection of personnel who will treat the sick child. In a simple manner, this means that a pediatrician should be emotionally and professionally invested in the service of the child (almost like a child's lawyer) in all dimensions. This course requires specific professional expertise and psychological training for pediatricians. In our region, the focus is currently on professional education only (Bross 2009).

Psychological preparation of staff does not exist at the moment. A holistic approach in treating children does not actually require any additional investment. There is only a need to change the attitude and behavior of physicians and nurses toward the child and parent. This would encompass the following:

- The hospital environment should be designed to avoid discomfort, embarrassment and fear.
- Upon admission, parents and close family should be permitted a 24 hour presence with the child, with house rules that prevent interference from staff engaged in their daily duties.
- A friendly atmosphere should be always encouraged and created with toys, books, music or movies.
- Always find time to talk with the child's parents, no matter how much work lies ahead. Take account of seemingly little things such as the body position on the same physical level as parents or child (e.g. sitting, standing) as it relaxes the parents and children and poses doctors as "friends of the family."
- Do not allow any interference by other staff in conversation with parents, which makes parents the center of all hospital events. Only emergency resuscitation of a life-threatened child is the only valid reason for interrupting the communication with parents.
- Staff should be familiar with the parents by name (surname), especially the particular doctor or nurse on duty that day or while caring for a child.

Explanations should be simple and understandable to parents. Always take into consideration parental dilemmas, fears and questions, and find time to answer them. Never forget that a child is never merely borrowed from their parents until the point of recovery. The hospital primarily serves the interests of children and parents, and medical staff serve the interests of the community. There is no place for arrogance and rudeness in children's hospitals at any level of professional organization (Mihic 2010).

Treatment that ignores the emotional problems a child and their parents is not complete, and is considered invalid and poor treatment. Everyone involved in the care of children (nurses, medical students, doctors, interns, residents and pediatricians) should be familiar with these issues

Although during a time of material shortage in health care it is unpopular to talk about changes that require greater involvement of the staff, there should be strong insistence on the resolution of this delicate issue.

There should be no fruitless vanity that does unfortunately exist in medical practice when dealing with such problems. Activities in this area in the future will certainly reduce problems in everyday practice, such as fear and uncertainty, introversion or aggression in the child, the parents' insecurity, and the need of some parents in our region to seek for very popular "intervention" from a higher social and political level. Such practices would increase confidence in our hospitals and staff, which generally gets a passing grade for the "technical value" while "artistic impression" remains weak or negative.

### **Suggestion for action**

Nine years is behind us after the implementation of Child Friendly Hospital in Mostar University Center. However, we still need promotion and support of ideas from the basic Project. It seems that we have forgotten previously set goals. Therefore, we propose:

1. Holistic approach to the introduction and training in pediatric practice (i.e. appreciation of the emotional problems of child and parents) in all institutions dealing with the treatment and care of the child (medical schools, faculties, departments).

2. Gross action by all who participate or will participate in the treatment and care of the child (nurses, students, trainees, physicians- specializing and specialists) in the implementation of learned and adopted principles of the program of Child Friendly Initiative.

3. Initiative should be focused on hospitals and clinics for children and engaged in the world's tendency that every hospital becomes in its content Baby Friendly Hospital.

4. Ask for financial support for the development and dissemination of promotional and educational materials, similar to Baby Friendly Initiative and the Ten Steps to Successful Breastfeeding.

5. Work on the evaluation of own results, collect and compare experiences from own and other communities, work out and modify own results against current cultural conditions without losing basic leading idea: Baby Friendly Hospital.

Children's Hospital Mostar received from UNICEF the prestigious title of Child Friendly Hospital in 2004. Beginner's enthusiasm and progress in a holistic approach to child has waned in recent years. It is, therefore, necessary to continue education of medical staff in a specific "humanity" program to protect children.

The ability of mature communication within the pediatric teams, open to the "new" and the continuous improvement of professional and human skills, seems to play a major role in maintaining the superior humanistic standards.

Although in recent years a lot has been said and written about these issues, the fact is that every person themselves assess the goals they have achieved. Only a realistic assessment of the "working environment" and human maturity in communication between patient-parent-physician, is a basis for successful progress on the default path.

## Conclusion

Methodical, complete and practical care for the smallest and most vulnerable part of the society should be the mission of the whole community. All who participate in education and in child- and family-centered practice should have the same goal:

To be a friend, protector and advocate of the child in the harsh world which spares no one.

To reduce and eliminate unnecessary suffering of children in the world that is already full of suffering.

To achieve this goal, only one thing matters: change the attitude. The child is a whole person from the beginning of their life. As a tender plant in a field, the child should be taken care of on fertile ground and needs a hand that will cultivate it ([www.unicef.org/specialsession/wffc/](http://www.unicef.org/specialsession/wffc/)).

**Acknowledgements:** None.

**Conflict of interest :** None to declare.

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Children's cognitive competence is defined by skills in language and communication, as well as reading, writing, mathematics, and problem solving. Children benefit from stimulating, challenging, and supportive environments in which to develop these skills, which serve as a foundation for healthy self-regulatory practices and modes of persistence required for academic success (Gottfried, 2013). Parenting knowledge, attitudes, and practices. For example, practices are related to knowledge and attitudes, and often involve the application of knowledge. According to behavior modification theory (Ajzen and Fishbein, 1980; Fishbein et al., 2001), a person's attitude often determines whether he or she will use knowledge and transform it into practice. Purpose: To describe nurses' knowledge and attitudes about relieving children's pain, perceived barriers to optimal pain management, and analgesics administered by nurses in relation to levels of children's pain. Study Design and Methods: Data were collected from 67 nurses and 132 children in their care. Clinical Implications: Nurses in practice need to become more aware of the adequacy of their analgesic administration, the value of children's self-report of pain, and the limitations of relying on children's behavioral manifestations to judge pain intensity. This study also demonstrates the importance of examining attitudes about children's pain relief and learning more about respiratory depression in children receiving opioids. Knowledge, attitudes and practices (kap) study on children with disabilities. conditions of absolute poverty; the latter is commonly aligned with populations with special educational needs and disabilities (SEND), irrespective of country location (Singal, 2013). One of the challenges for Bhutan is to ensure that all children with SEND receive appropriate education and social services (Ugyen and Cokl, 2010).