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EDITORIAL

Pediatric palliative care

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Advanced medical technologies and specialised care have reduced the neonatal and pediatric mortality rate considerably in the last decades in modern society. These technologies have led to a longer survival of young patients diagnosed with severe, potentially lethal diseases, without always succeeding in curing them. Therefore the number of children with life-threatening diseases increased; the international literature indicating a prevalence of incurable disease annually affecting 10/10,000 young people from 0 to 19 year old. Accordingly to the official statistics 4467 children with cancer were registered in Romania in 2005; almost three times more were diagnosed with other non-oncological progressive incurable diseases. Every year around 500 new cases of cancer in children are detected in Romania.

For parents, the information that their child suffers from an inexorable disease that leads to a premature decline comes as a devastating shock. The emotional and practical burden of caring for a child who has a limiting condition is huge for the parents, so pediatric palliative care should focus on the family as a whole, more than in adult patients. In addition, the parents together with the doctors who care for the child are faced with difficult decisions regarding treatment and the benefits of medical technology versus the burdens and their impact on quality of life. It is therefore important that physicians and palliative care team work closely with the family of the sick child to take decisions that are the most beneficial to the patient, while holding true to the values of the family.

The care needs of infants, children and teenagers with severe progressive diseases which can lead to death or a life of severe disability are profound and require a supportive approach and on long term in specialized pediatric palliative care centers. By definition, pediatric palliative care refers to the active and total approach to care of the child's body, mind and spirit. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and support for the families around death and during bereavement. The goal of palliative care is the achievement of best quality of life for patients and their families in accordance with their values, regardless where care is provided: in hospital, at home, in hospice facility or other community centers. Unfortunately, international studies show that the access of children with life-threatening diseases to specialised palliative care is limited and often depend on the geographical area in which the child lives or on the type of the disease involved (generally they are more available for children who suffer from cancer). Ideally these services should be accessible to all eligible children who are diagnosed with conditions that threaten their lives – at the proper time and in any situation when is considered that the sick child and the family can benefit from this type of care.

The American Academy of Pediatricians supports an integrated palliative care model, „in which the components of palliative care are offered from the diagnosis and continued throughout the course of child's illness, whether the outcome ends in cure or death”. Limiting palliative care for children who have exhausted every curative treatment and are dying would mean that many other children would miss the benefits that palliative care can offer. The inclusion of children with life-threatening or limiting diseases/conditions who are still under

the curative treatment, ensure that all children who can benefit from palliative care, have access to it.

In conclusion, the vulnerable category of children with life limiting conditions deserve a profound organizational and cultural reappraisal of how we care and support them because the aim of care is not (only) recovery, but also offering the best possible „health” and „quality of life” in the context of their disease.

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ORIGINAL PAPERS

Assessment of symptoms in advanced cancer in children

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Abstract

Objectives:

The aims of this study are to:

- assess the type and frequency of the symptoms in advanced cancer in children being cared for by "Casa Speranței" Brașov, Romania;
- see if all recorded symptoms are approached in the individualised care plan;
- compare the symptom evaluation and the response to treatment recorded in our files with what was perceived by parents or carer.

Methods:

We review the medical records of all children who died of cancer between 1996 and 2008 in our care service. In this period 94 children died, of whom 51 by cancer

Criteria for inclusion: to have at least one complete evaluation of symptoms. We analysed all the symptoms using descriptive analysis with SPSS.

Results:

Thirty nine different symptoms were identified. The most common symptoms were pain (100%), lack of appetite (87%), astenia (87%), constipation (73%), nausea (71%), dyspnoea (60%), cough, irritability (67%) and anxiety (60%).

Pain was controlled in 60% of our patients, better than dyspnoea (10%) and nausea (50%). Anorexia, fatigue, irritability were frequent rated in our survey, distressing a lot the parents. Not the same attention was given in managing psycho-emotional problems as compared to physical problems.

The parents survey showed that the palliative team intervention - in the opinion of the parents - contributed to better symptom control, and quality of life in children with advanced cancer. They especially appreciated that their child was able to be cared for at home most of the time, giving the family the possibility to spend time together

Conclusions:

All the deceased children experienced substantial suffering in the last period of life. Pain was better controlled compared with dyspnoea and nausea.

The palliative care service contributed a lot to the improvement of quality of life for the children and their families and made possible that the majority of children died at home.

Key words: *palliative care, children, cancer, symptoms, quality of life*

(Full text in Romanian)

‘Out-of-hours’ pediatric palliative care in Belarus: current arrangements and perspectives

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Abstract

Introduction:

‘Out-of-hours’ care is a team approach to cover complex needs of patients and his family. For this purposes, a good legislative base and organizational system should be created in Belarus to give equal opportunity for patients in cities and villages to get high quality care and access to the necessary professionals, drugs and equipment out-of-hours.

Method:

Recent developments in palliative care and policy are described based on registration data and experiences in the Belarusian Children's Hospice, official reports and legislation.

Conclusions:

Different tools for improvement can be used in hospice and government institutions (incident report, service review and audit). The essential issue is the establishment of a good educational and information system for caregivers and trainers as well as for patients. Good experience of children’s hospice can be useful for the governmental model of out-of-hours palliative care.

Key words: *out-of-hour care, pediatric palliative care*

Introduction

Pediatric palliative care was launched in Belarus in 1994 by founding a non-governmental charity organization “Belarusian Children’s Hospice” in Minsk which provides now complex care for 200 children (1, 2). There are an in-patient department, a day stationary department and home-care service in the hospice. A mobile team has been organized for children living within the 250-km zone around Minsk. Providing in-patient and home-based palliative care for oncological and non-oncological patients aged from 0 to 24 years with life-limiting conditions, the hospice admits children from the whole country into the 3-bed department for the end-of-life care, respite care and “transit stays” for symptom control. The hospice team consists of doctors, nurses, psychologists and social workers; it has a close relation with hospitals and polyclinics, referring children for palliative care. In 2010, the hospice launched a home care team in Gomel city for 50 families.

‘Out-of-hours’ pediatric palliative care

Aim of ‘out-of-hours’ palliative care is to cover medical, psychological, social and spiritual needs of patients with life-limited conditions and to support their family outside the working hours regardless the place of staying (at hospital/hospice or at home).

Current arrangements for ‘out-of-hours’ care at the hospice

Belarusian Children’s Hospice provides palliative care 7 days per week ‘round-the-clock’: by home care team (visits and on-call) for children in the cities of Minsk and Gomel; and by mobile team (telephone consultations) for families outside the cities. Visits and on-call

consultations made during the previous day, problems, and solution strategy are discussed at the morning meeting of the hospice team daily. Time, purpose and result of on-call communication are registered in a journal; visits are registered in individual patient's documentation.

The 118 families supported by the home care team in Minsk are divided between 4 nurses making visits "by plan" in the working hours and "by family request" out-of-hours. In case of the child's dying, a 24-hours duty of nurse can be available at the patient's home. If family prefers to stay in the hospice, a 24-hours nursing is organized by contracting nurses. Other members of palliative care team also make visits 'out-of-hours'. By my observation, they are requested mainly for on-call communications with a duty nurse, child and family, support services, etc.

Quality level of out-of-hours service provided by the hospice in Minsk and Gomel based on international standards is very high and allows patients to receive appropriate palliative care at home including medical and non-medical support, and drug/equipment provision. During the last five years all children receiving 24-hours hospice care at home died at home.

In cases of settlements outside both cities, it is very difficult to avoid admissions into hospitals/hospice in crisis situations and dying despite 24-hours on-call communications due to absence the possibility to visit patients as needed. More than 50% of the hospice's patients from small cities and villages died in hospitals. (1)

Current arrangements for out-of-hours care for the community

In Belarus with population of 9.5 million people, health services are mostly governmental with 8-hours working day and weekend services. Contracted doctors and nurses work outside the main working time in hospitals but not at district polyclinics for home care.

The non-governmental sector, accounting about 5%-10%, includes private out-patient curative medical service; palliative care service is provided by the only Belarusian Children's Hospice with a license of the Ministry of Health.

Out-of-hours palliative care for the community has not been organized. Only emergency ambulance service proposes a medical aid for emergency conditions, pain control with morphine and urgent transportation to the hospital 24 hours 7 days per week. There are 24-hours pharmacy shops selling medicines except opioids at every city's district but none in province.

If a patient is admitted to the hospital, he cannot receive out-of-hours non-medical support (emotional, spiritual, etc.). This is an unsatisfactory situation because there are cases of adult suicides not only at home but even in hospitals during out-of-hours.

Deficits and problems

The list of deficits and problems observed in out-of-hours care includes:

- lack of professional knowledge, protocols, standards and well-organised service;
- a frequent use of emergency ambulance for symptom control and high level of hospital admissions out-of-hours due to absence of non-parenteral medicines and necessary equipment at home resulted in an inadequate symptom control;
- poor pain control at home because of absence of oral morphine and shortage of non-parenteral opiates which influence negatively on the public opinion that cancer pain is impossible to relief at home;
- suicides during out-of-hours due to absence of professional medical and psychological support delivered by "hot" telephone lines;
- deficiency of accessible and comprehensive information about algorithms in emergency/crisis situation which can be obtained by patients and its family out-of-hours;

- poor management of a child with complex needs due to absence of interdisciplinary teams;
- absence of special standards and algorithms for health care professionals how to meet the needs of special groups of patients out-of-hours (oncological and non-oncological, HIV/AIDS, pediatric, geriatric, cultural, religious, sexual, etc.);
- poor interaction between health care professional in different clinical areas and between institutions;
- fear to ask a help due to poor communication skills in medical professionals.

In my opinion and accordingly to views of others in our team, the general barrier is the absence of general understanding in the community about the importance of out-of-hours palliative care services. The main barriers in out-of-hours service in Belarus are:

1. Poor legislative base:

- for regulation and standards to create interdisciplinary team (child and family members, medical service, social service, school, others);
- for quality measure (control, accreditation, assurance and improvement) and quality control;
- minimal government standards for treatment and social support, guaranteed for every resident, do not include palliative care;
- the term “palliative care” is not included in Law of Health, the specialization in palliative care cannot be introduced.

2. Poor educational system and absence of trainers:

- palliative care is not included into the basic program of education; it is studied as a short postgraduate course;
- caregivers have no communication skills and they do not understand what they can and have to do during the main work and out-of-hours: half of children with incurable malignancies are admitted to hospitals during out-of-hours or not referred to the hospice from oncology centres, dying at intensive care unit because of the lack of knowledge of health care professionals.

3. Restricted drug policy which negatively influence on production and prescription of opioids:

- no oral morphine and codeine;
- no parenteral hydromorphone;
- a continuous infusion of opioids is prohibited at home.

4. Poor resources in the country and difficulties with fundraising.

5. Poor reflection of society and government on needs of disabled people.

Ways to improvement

In Belarus, 1500 of 2 million children need palliative care including 50 patients with malignancies per year (1). It is impossible to take care for all these children by one hospice. Charity resources and launching of new non-governmental hospices are limited in Belarus. A governmental palliative care service is required.

The first palliative care regulation document was passed by the Ministry of Health for children’s hospitals in 2008, however, without any results because of absence of responsible persons and educated staff.

In order to coordinate government activity and to improve the educational process, the National Resource Centre for Pediatric Palliative Care was founded in 2010 and the main specialist of the Ministry of Health in pediatric palliative care was assigned in 2011, i.e. the author is assigned to this position and involved into the policy development.

With my participation, new regulation documents have been passed by the Ministry of Health for palliative care departments in Baby Houses in 2011 and for establishment of governmental palliative care service at home in 2012. Procedure of referring to palliative

care, information consents, individual care plan with algorithm in crisis situations, standards of care have been developed as well.

As a shortage of specialists trained in palliative care still exists in Belarus, a centralized general training of pediatricians and nurses from local/district polyclinics and hospitals has been started since 2011 at working places additionally to the 2-week Palliative Care Educational Course running at Belarusian Medical Academy for Postgraduate Education since 2000.

The medical university and nursing college in Minsk will include palliative care into the educational program. Training for trainers will be organized in 2012-2013 by Belarusian Children's Hospice specialists with help of foreign professionals. Proposals for overcoming the existing barriers are prepared now by our team for the Ministry of Health.

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CLINICAL LESSONS

Suffering and grieving. Unique aspects for a child

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Abstract

The childhood period is characterized by a fast development of all physical, emotional and cognitive components that mobilize the entire energy of a child. In case of grieving the necessary resources for the grieving period will diminish the energy resources utilized in the child's growing and developing process.

In case of bereavement, the psychoanalytical literature uses the concept of "lack of pain" for children based on the hypothesis that they are not able to experience the intense effects of the bereavement. Therefore, children are often suffering alone because they are considered to be "too young" to understand what is happening. However, the process of grieving is related to age, the intellectual and emotional development of the child and the circumstances in which the loss took place.

Children who have to deal with AIDS related deaths can witness the death of other family members or they themselves can be HIV+. They are exposed to the risk of complicated suffering. The infant infected with HIV doesn't realize the extent of the drama, he starts by not knowing what death is and because he does not understand, he denies it.

The concept of "lack of pain" in the case of children was incorporated in the psychoanalytical literature since its beginning. The clinical phenomenon of pain for a small child is rarely described or analyzed in the psychiatric literature. The early theoreticians sensed that the bereavement takes place starting with the adolescent phase because of the infant's psychological structure.

The reactions of pre-scholar children who loose a beloved one have mostly been under reported or neglected.

This paper analyzes the stages of the children's development from a suffering process perspective. We will also present a complicated bereavement case of a 5 years old child.

Key words: *death, children, psychological development, pain, complicated bereavement*

(Full text in Romanian)

Case presentation: palliative care of a child with incontinentia pigmenti

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Abstract

This paper presents the case of a 1-year-old girl, known with pigment incontinence, diagnosed with hydrocephalus secondary to giant meningoencephalitis, untreated due to underlying disease, with a rather limited prognosis.

The girl has multiple hospitalisations, due to a fulminating increased head perimeter and to different complications (parietal bedsores, denutrition due to low digestive tolerance) and also for adequate control of symptoms and very close monitoring.

The paper describes the problems and interventions provided to the little girl, with 24 – hour evaluation and final review at discharge.

Keywords: pigment incontinence, hydrocephalus, decubitus, hyper pigmentation, pain

(Full text in Romanian)

Palliative care in a case of the bladder exstrophy

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Abstract

The bladder exstrophy diagnosed patient needs a good skin and lesions care management. The definition of bladder cloacal exstrophy, frequency of the illness, causes, treatment, and prognosis are described as well as one patient cared for by the pediatric team of Hospice "Casa Speranței".

The palliative care we delivered consisted in observing the patient in the hospital where she was treated, interviewing the family members, examination of the lesions and skin damages. Also we facilitated the communication with the doctor and the nurse in the hospital in order to follow the care process during the evolution of patient illness.

The care consisted in:

- efficient lesions care, irrigation and using lotions, bandages and keeping the moisturized environment to facilitate the healing of the wounds.
- pain control.
- financial support (bandages, lotions, medication, colostomy bag, syringe, etc.).
- facilitating the connection with Ortopedica (Râmnicu Vâlcea) in order to get the colostomy bags.
- counseling and preparation of a file containing the medical records of the patient in order to be presented to specialized clinics from foreign countries.

From the mothers' personal observations, following the given treatment, the abdomen was healed, making possible the set up of the colostomy bags. The palliative treatment joined and completed the curative one.

Key words: *bladder exstrophy, palliative care*

(Full text in Romanian)

Palliative approach on insomnia in children: a case study

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Abstract

Motto: „ Even when you think you can't do anything, something still can be done.”

Introduction:

The pediatric Inpatient Unit of „Hospice Casa Speranței” becomes often a second home for young patients, and medical frames „replace” parents. There are multiple methods that can provide the necessary support to the patient and care of the child properly during the admission, providing accurate and concrete solutions to their problems.

Objective:

The present work aims to outline the holistic, multidisciplinary approach to deal with problems which appear at admission in the unit, focusing in particular on the psycho-emotional problems. Especially, the case presented deals with the most recommended interventions for treating insomnia in children.

Method:

Presentation of cases by evaluating the patient data on the sleep-wake status prospectively. Also, we describe agitation of a child with severe insomnia due to anxiety.

The following data were monitored:

1. The schematic approach of problems;
2. Identification of causes of insomnia;
3. Monitoring the state of anxiety and insomnia on the repeated admissions, using the tools of German study- table set;
4. Therapeutic strategy applied by each team member;
5. Non-pharmacological and pharmacological interventions;
6. Therapeutic methods applied by the nurses and their efficiency;
7. Assessment of advantages and disadvantages of using sleep status tray table advertising.

Conclusions:

Our daily work invades countless into our private space, children's faces following us home. New methods are applied which helped efficiently to improve the quality of life of children as well as the psycho-emotional balance of medical professionals, so much needed in order to be able to continue daily work.

A holistic approach to the problems of patients is important to give patients quality services and knowledge and practical skills are needed. But also, we need the right attitude, compassion and dedication to be able to respect the right to dignity of each patient and to give the value of each day they live.

Key words: *palliative care, insomnia, anxiety, multidisciplinary team, table*

(Full text in Romanian)

MANAGEMENT

The management of Duchene Muscular Dystrophy from the moment of diagnosis

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Abstract

Introduction:

Life and its miracles start with a small egg, grows within 3 weeks, when the first heart beat can be perceived. A new life is started! This life has a mystery – the genetic code. In the case of patients with Duchene Muscular Dystrophy (DMD) genetics has forgotten to write in its code a few letters and squares, and the line of a 'normal life' is changed.

The parents of the children with a diagnosis of DMD face numerous questions about the causes of the disease, the prognosis and especially the care of their child,

Objective:

This paper presents the management and the standards of care of patients with DMD, reached through national and international consensus.

The management of these patients must include:

- access to information regarding genetic tests for patients and extended family (sisters, cousins, daughters);
- information regarding the evolution;
- information regarding the National Register of DMD standards and DMD parents' association (Patent Project – APP) and implementation of the National Plan for Rare diseases in Romania;
- enhancing quality of life through complex, interdisciplinary care for maintaining and for prevention of deformities, i.e. good respiratory function, good nutrition and psycho-emotional support for child and his family.

Conclusions:

The dialog between partners – patients diagnosed with DMD and their families – shows the impact of DMD on the family, and thereby their need for the interdisciplinary professionals team, which can offer equal access to quality care and the opportunity to benefit from new treatments and complementary therapies.

Key words: *palliative care, Duchenne Muscular Dystrophy, management*

(Full text in Romanian)

Palliative care for children in Russia: some steps forward

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Abstract

Objective:

The aim of this analysis is to describe palliative care for children in Russia and perspectives for its development. We adopted a multisession approach, which involves the synthesis of evidence from published literature, internet resources, local expert's interviews and personal communication.

Method:

Data have been gathered from the following sources: (1) published articles in peer reviewed and professional journals, (2) books and monographs, (3) palliative care directories, (4) palliative care web sites, (5) grey literature and conference presentations, and (6) the experts' opinions.

Results:

Basically palliative care is provided by specialists in diverse pediatric clinical settings and by mobile teams in the community. We have found independent palliative care services for children with cancer in 8 cities within the country. Pioneering programmes have been introduced in a number of cities. These programmes involve collaboration between state and nongovernmental organizations and have grown up primarily through the inspiration of local leaders.

Conclusions:

There is evidence of wide-ranging initiatives designed to create the organization, workforce, and policy to develop capacity for hospice-palliative care services for children.

Key words: pediatric palliative care, hospice, Russia, capacity building activity

Introduction

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, containing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (ACT definition) (1).

Evidence from the literature and personal communication suggest that there is a growing awareness of pediatric palliative care across Europe but comprehensive services are still not part of national health plans in most countries (2).

The specific needs of children with cancer and other life-limiting conditions and their families often went unnoticed. Although medical services were available for these children, their emotional and spiritual needs were largely overlooked. Pediatric palliative care in Russia is an emerging subspecialty that focuses on achieving the best possible quality of life for children with cancer and their families.

The aim of our study was to describe palliative care for children in Russia and perspectives for its development.

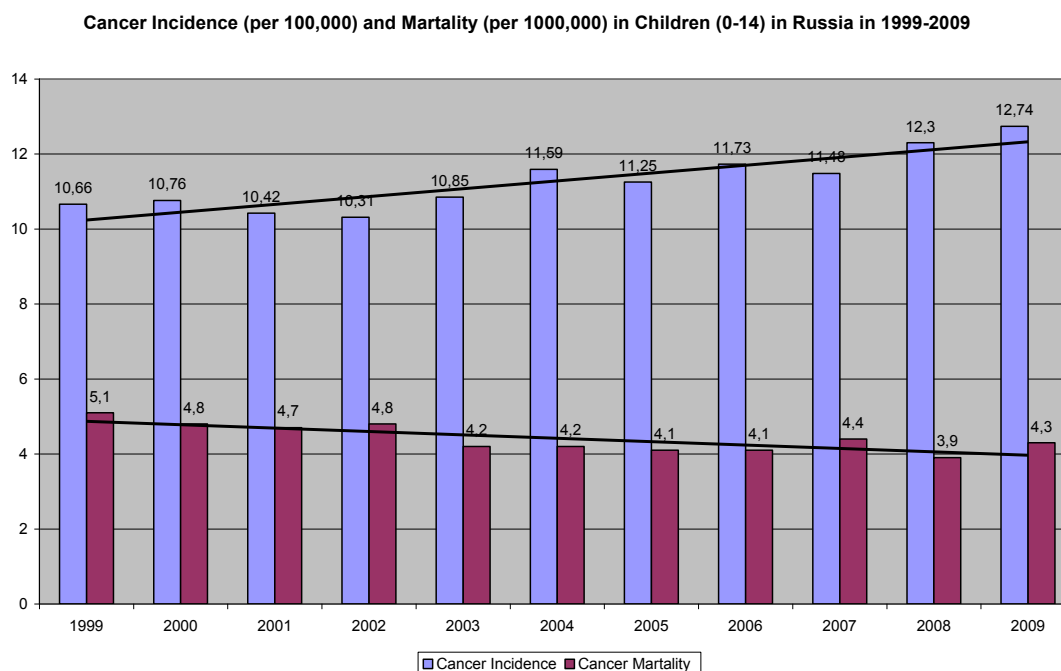
Methods

We adopted a multisession approach, which includes the synthesis of evidence from published literature, internet resources, local experts interviews and personal communication. Data have been gathered from the following sources: (1) published articles in peer reviewed and professional journals, (2) books and monographs, (3) palliative care directories, (4) palliative care web sites, (5) grey literature and conference presentations, and (6) the experts' opinions.

What do we know about cancer in children?

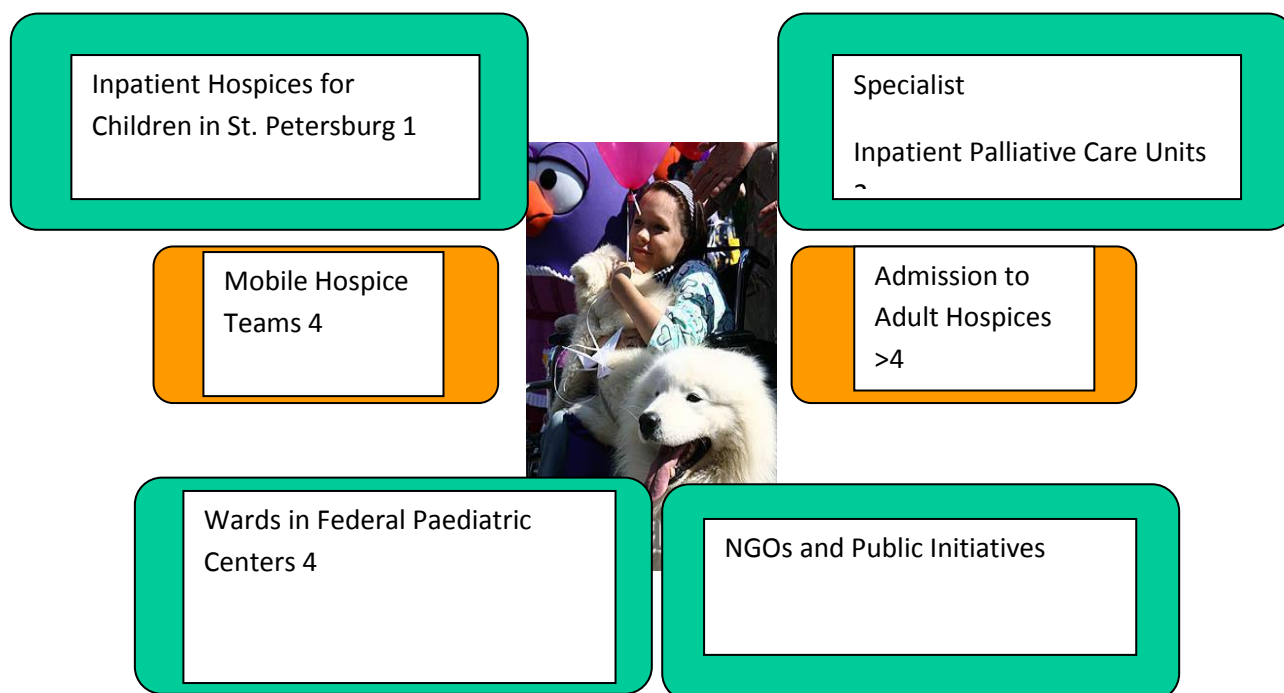
Russian Cancer Statistics 2009 contains a special section on pediatric cancer (under the age of 15). In 2009, 2,706 (2,577 in 2008; 2,927 in 1998) children were diagnosed with cancer in Russia and 1128 died in 2009 (818 in 2008). In 2009 the overall incidence of childhood cancer was 127 per 1,000,000 (123 in 2008; 103 in 1998), 19.6% cancers were diagnosed in advanced (IV) stage (10.1% in 2008; 8.7% in 1998), and the one-year survival ratio was 88.1% (84% in 2008). In 2009 the rate of death from childhood cancer was 43.0 per 1,000,000 (39.0 in 2008) (Figure 1) (3). Annually around 4.5 thousand new cancer cases are registered in children and adolescents in Russia.

Figure 1- Cancer incidence (per 100,000) and mortality (per 1000,000) in children in Russia in 1999-2009



Basically palliative care has been provided by specialists in diverse pediatric clinical settings and by mobile teams in the community. We have found palliative care services for children with cancer in 8 cities (hospice/palliative care units; home teams or wards in adults' hospices and in specialist pediatric centers). The most services (eight) are based in Moscow. According to the Health Ministry there are currently seven independent specialist palliative care units for children within the country (Figure 2) (4).

Figure 2 - Specialist palliative care units for children in the country in 2011



Pioneering programmes have been introduced in a number of cities. These programmes involve collaboration between state and nongovernmental organizations and have grown up primarily through the inspiration of local leaders.

The role of all-Russian and local NGOs and public initiatives is vital. The two major public initiatives were launched by Dr. Arkady F. Boukhny and Dr. Marina A. Bialik in 2003 and the information project entitled Pediatric Palliative Care Initiative for Russia was started. The mission of the initiative was to raise the quality of care provided to children with life-threatening diseases.

Later the powerful palliative care advocacy initiative “The Angel’s House” was launched by Elena Zonova in Moscow with the aim to push forward pediatric palliative care development in the country. The first hospice for children has been set up recently in St. Petersburg. There are a lot of NGOs and public initiatives that support medical care for and social wellbeing of children with cancer all over the country.

The data were analyzed using the typology’s key elements and the country was allocated to the category: Capacity building activity (5). There is evidence of wide-ranging initiatives designed to create the organization, workforce, and policy to develop capacity for hospice-palliative care services for children. Activities include: attendance at or organization of key conferences; personnel receiving external training in palliative care; lobbying of President of Russia, policy-makers, and health authorities; and an incipient service development, usually building on existing home care programs.

Below the major palliative care programmes for children in the country are listed:

- Large palliative care public initiatives, e.g. “The Angel’s House” All-Russian Campaign was launched with the aim to push forward pediatric hospice care development in the country. The leaders of the all-Russian public campaign “The Angel’s House” have addressed to President and call on him to support adoption of a law on palliative care and establishing inpatient children’s hospices in Russia.
- New hospices and palliative care services are scheduled to start in 9 regions. The need for children’s specialist palliative care today has been recognized and seems to become an

integral part of the health system. Two specialist inpatient palliative care units have been already started.

- Enormous contribution to palliative care for children development has been made by the Charitable Fund "Give Life" ("Podari Zhizn"). The Pediatric Palliative Care Unit in the Medical Care Center for Children, set up in 2010, is supported by the charity Give Life. Over the year more than 70 children have received treatment as in-patients in the unit and 200 are registered for day care. These are children up to 18 years with terminal illnesses such as cancer. The centre has various forms of pain relief, including drugs, and other kinds of treatment such as intensive care. It is funded by the municipal budget supported by charitable donations.

- The first ever inpatient children's hospice was launched in St. Petersburg (2010) and the Children's Palliative Care Department at the Research Medical Center for Children with Congenital Craniofacial Anomalies and Neurological Disorders in Moscow (2010).

- Children's cancer web site <http://pediatriconcology.ru/> has been recently launched.

Two years ago the Health Ministry started the work on the document entitled "Procedure for palliative care provision for children". According to experts' estimates, in Russia there are some six thousand terminally ill children who need palliative care, of which about one thousand - cancer patients. Among terminally ill children up to 20% have cancer diagnoses. The others - are patients with diseases of the nervous system: congenital or acquired (4).

For the first time a definition of palliative care is provided at state level in Russia, i.e. in the draft of the new Federal Law "On health protection in the Russian Federation", which was submitted to the State Duma of the Russian Federation and passed on the first reading by the State Duma on May 30, 2011. There is an article in the draft (Article 42, the edition 30.07.2010), which defines palliative care as a set of health measures provided to citizens suffering from an incurable, life limiting progressive disease, with an aim to improve the quality of life of patients and their families. The Draft states that palliative care in medical institutions should be provided within the framework of the state guarantees for provision of free medical care to citizens along with primary care, specialized and emergency medical care (Article 75).

As the Health Ministry states: in 2011-2012 palliative care units will be established in 74 regions and the government will allocate funds for their work. The organisational forms of palliative care units will be defined by local administration. To a great extent everything depends on the needs and opportunities of the region.

Today the world of children's palliative care has begun to change in Russia. There are at least some palliative care services and a dedicated workforce. A new law and guidelines for pediatric palliative care are on the way. Children's palliative care is not nationally regarded as a specialist area yet. We still have a long way to go. We must work hard and unite efforts of different institutions and organizations to ensure that these children and their families remain centre stage.

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COMMENTS, DISCUSSION

Particularities of palliative care for children

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There are many similarities between palliative care (PC) for adults and children, but there are also differences which need to be acknowledged when someone wants to develop PC for children.

The common aspects include: prognosis; multiple symptoms which will bear upon the quality of life and will restrain progressively the activities of the patient; distress of the whole family; emotional impact for the staff; need for a co-ordinated, interdisciplinary approach.

The aspects which are different in PC for children are:

1. The number of children who die is small comparing with adults. This means that a service has to cover a much larger area, and also the lobby for such a service is more difficult.
2. Many diseases are rare, specifics for pediatric. This means that the majority of professionals will lack the expertise for a specific disease. There is a strong need to cooperate with specialized tertiary units, but also with local hospitals and family doctors. A special challenge is the transition in the adult care.
3. The time of care varies considerably: from days or months to many years. This will usually leads to exhaustion for the families/ carers. Therefore an important part of PC for children is respite care service.
4. Many diseases are hereditary, so it is possible to have more children affected in the same family. They need genetic advice and family counseling as they may deal with guilt and family tensions.
5. There are many misconceptions regarding pain and use of opioids in infants and small children which need to be addressed and overcome through specific education.
6. The majority of the children needing PC are neurologically and intellectually affected, resulting in difficult symptom assessment. Therefore the staff needs special communication abilities and to use special evaluation instruments.
7. The child is not legally responsible, he depends of the parents' decisions. This will have ethical implications in dealing with the child autonomy and the parents wishes. The whole family needs ongoing support. That is why in CPC the unit of care is the family.
8. The children are in the process of developing and they need to continue their education. One role of the PC team is also to mediate the relation with schools in order to ensure this right of the patients.
9. The children physiological and pharmaco-kinetic particularities will influence the nutrition, hydration and the choice of medication and dosage.
10. Some drugs are not licensed for children, or are not accessible in oral form. In these cases extrapolation from the adults doses and the use represent the best practice.

In conclusion, for organizing palliative care services of children one needs expertise in pediatrics and palliation as well as good co-operation with lots of children services, including hospitals, family doctors, child protection authorities and schools.

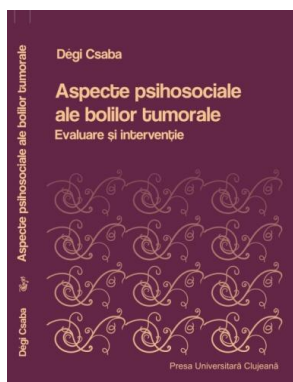
Key words: *pediatric palliative care, particularities*

NEW PUBLICATION

Psychosocial aspects of cancer diseases. Assessment and intervention

Dégi L. Csaba
Cluj Napoca: Presa Universitară Clujeană;2011

Assessment of distress and quality of life in cancer patients has equal importance to reveal the biopsychosocial etiology and cancer risk, since quality of life is a significant prognostic factor of cancer progression and mortality, comparable with medical and treatment-related factors. For example, in the past 20 years, the high proportion of unmet, untreated psychosocial needs in cancer patients has not changed, except for significant progress in pain relief, alleviation of adverse reactions to oncologic treatments and the significant development of psycho-oncology, meaning increased awareness of the fact that psychosocial factors influence physiological processes which stimulate carcinogenic growth and invasion.



The basic aim of this book is to explore and examine cancer-related distress and quality of life aspects in Romania. Present research on the psychosocial aspects of cancer was started by applying the biopsychosocial research framework. In this clinical study the author puts emphasis on psychosocial aspects (e.g. diagnosis, depression, and quality of life), because objective characteristics, such as particularities of tumors, give uncertain indications for understanding how cancer patients cope with the chronic condition.

This study investigated the actual biopsychosocial and spiritual state of hospitalized adult cancer patients in Transylvania, Romania, and their well-being (quality of life). The relevance of this clinical research should be addressed and evaluated starting from the fact that in Romania there are no relevant, scientific data about cancer diagnosis non-disclosure, cancer distress (depression and anxiety) and cancer-related quality of life, based on multivariate statistical analyses. Also, we have no knowledge of psycho oncologic studies, such as surveys carried out on large hospitalized samples in Romania. According to the tumor location this heterogenic, mixed sample included 420 adult oncology patients, 342 with malignant and 78 with benign tumors.

Results show that 17% of cancer patients are not aware of their oncologic diagnosis, 47% are clinically depressed, 47% experience anxiety disorders and 28% report critically low quality of life. Almost nine out of ten patients suffering from clinical depression and with low quality of life are patients with malignant cancer diseases. Three quarter of cancer patients who report low quality of life are also facing clinically relevant depression symptoms. Moreover, almost two-thirds of cancer patients to whom cancer diagnosis was not disclosed are highly or severely depressed.

One of the most important findings is that cancer diagnosis non–disclosure, clinically significant depression and seriously decreased quality of life are more prevalent among persons with malignant tumors and among older, undereducated, widowed and socio–economically deprived cancer patients.

In this psycho oncologic dissertation, the investigated psychosocial variables were independently related to cancer diagnosis disclosure, cancer–related distress and well–being, quality of life, and were significant prognostic factors for cancer diagnosis non–disclosure, clinical depression and low quality of life.

NEWS

International Multi-Professional Pediatric Palliative Care Course

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Young people and children with life-threatening and life-limiting conditions have very unique and specific palliative care needs which are often different to those of adults. There is a big need for professionals to share a vision of the total needs of the patients which include physical, emotional, spiritual and developmental aspects of care.

Between May 05th – 11th 2012, the *Second International Multi-Professional Paediatric Palliative Care Course* was held in Haltern, Germany, organized by *Vodafone Foundation Institute and Chair of Children's Pain Therapy*, and also by the *Pediatric Palliative Care Children's Hospital Datteln*, Germany under the auspices of *The Association for Children's Palliative Care* and the *European Association for Palliative Care*. Two years ago the first International Pediatric Palliative Care Course was organised attended by nearly 80 paediatric palliative care professionals from all over Europe and even from other continents participated and very much enjoyed the course. This year around 90 professionals from 26 countries all over the world benefited from this course. Among them there were 13 Romanian professionals from three pediatric palliative care centers (Hospice Casa Sperantei – Brasov and Bucharest, Emanuel Hospice from Oradea) and from Children's Hospital Luis Turcanu, Timisoara.

The IMPPC Course brought together experts from around the world to exchange experiences, learn from each other and build networks. The objective of the course was to achieve significant improvements in care standards and the PPC structures throughout Europe and other countries. Every life-limited child deserves a high standard of total care, wherever they live in the world.

The course covered areas such as *Pain in PPC, Prescribing opioids in children, The Management of Dyspnoea, Palliative sedation in PPC, Fatigue, Involving children with life-threatening illnesses and life-threatening conditions in medical decisions, The Bio-psycho-social aspects in PPC, Burn out prevention, Spiritual Care in PPC, Challenges in PPC Education, The suffering of professionals and Childhood Bereavement*.

Besides theoretical input, participants had the opportunity to visit the Pediatric Palliative Care Centre from the Children's Hospital Datteln and to observe the multi-professional team at their clinical work on the ward. Also, participants were able to attend daily ward rounds and therapeutic sessions such as art and music therapy.

(Source: Dr. Boris Zernikow, 2. *International Multi-Professional Paediatric Palliative Care Course*, Haltern, Germany, 2012)

1st European Congress on Pediatric Palliative Care

The Maruzza Lefebvre D'Ovidio Foundation, in collaboration with the European Association of Palliative Care (EAPC), organizes the 1st European Congress on Pediatric Palliative Care in Rome from the 28th - 30th November 2012.

The aim of this initiative is to provide an international platform for interdisciplinary knowledge sharing where experiences, current topics and new perspectives on key issues regarding palliative care for children and their families can be debated, compared and discussed by those working with critically ill children throughout Europe and beyond.

Children's palliative care encompasses the clinical, psychological, ethical and spiritual aspects of care for children with life-threatening and life-limiting conditions. Children affected by these conditions have unique and multiple care needs that are very different to those of adults. Whilst in some countries child-specific palliative care services and practices have been in place for a number of years, in many others the recognition of needs and the development of dedicated paediatric palliative care services are still at an early stage.

For over a decade the Fondazione Maruzza Lefebvre D'Ovidio Onlus has been operating at a national and international level for the improvement and reorganization of palliative care practices for infants, children and adolescents. Since 2006, the Foundation, in collaboration with the European Association of Palliative Care, has supported the activities of the European Steering Committee on Palliative Care for Children and related EAPC Taskforces.

For more information visit the website: www.maruzza.org