PALIATIA

journal of palliative care

Volume 3, Number 2, April 2010

www.paliatia.eu

PALIAȚIA, Vol 3, No 2, April 2010 ISSN 1844 – 7058

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NEW PUBLICATION

Palliative care in HIV infection

NEWS

Drawing on the cover: Anonym, no title

EDITORIAL

“Steps from the past to the future of the palliative care in children with AIDS”

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Year 1990. The Colentina Hospital (at present, the National Institute of Infectious Diseases “Prof. Dr. Matei Bals”) became the central hospital to treat AIDS patients by regulation of Ministry of Health regarding the “concentration” of all AIDS patients in one hospital in Romania. Result: Colentina Hospital had to admit hundreds of children with AIDS, belonging to orphanages, centres for children and clinics for children with malnutrition, but also from families, who were afraid to take back home their own child after they found out the diagnosis of AIDS. Unfortunately, Romania was well-known for sheltering half of the paediatric AIDS cases of Europe.

The poor conditions, lack of the specific medicines and extremely high mortality at that time, were counterbalanced by an amazing attitude of caring for these children, who were deprived of affection and overwhelmed by physical suffering, learning to accompany the medical care by expressing feelings and so, to change the status of a lying child into a loved one, who is in the centre of care of the adult, being not necessary the parent, but taking the parent’s role, in a big family. We learnt to value not only the medical success, but also the “reward” of these children: a smile, a gesture of tenderness, a flicker in the eye. Even death came differently, lying in the nurse’s arms, they died “loved”! These steps we have made together with people who surpassed this stage of route in front of suffering through their experience in palliative care, opening the door to the principle of *“love, tender and care”!*

In a very short time we had access to international medical experiences in over a decade of AIDS care and also the chance of training by the multidisciplinary team of Dame Cicely Saunders, from St. Christopher Hospice. Taking over the experience of oncologic care we implemented the principle to focus on symptoms in case of an incurable disease in the care for AIDS patients.

Year 1996. David Ho launched the principle of HAART (Highly Active Antiretroviral Treatment) changing AIDS in a chronic disease and offering the hope of a normal life, which every day became true.

In hospitals with AIDS patients the concept of palliative care was taken over by that of infectious diseases, which were associated with security and comfort by the patients. Although it seems insignificant, to us it represented another step in offering complex medical care, needed by the AIDS patient. We built new bridges with the Romanian School of palliative care to pass from shy endeavours to a model according to the standards and protocols of good practice, as EU requires.

Year 2010. As the antiretroviral treatment changed the quality of life of people with HIV / AIDS we really believe that the palliative care will offer the right to AIDS patients to be treated as a person who is *still alive* , to be upholded to express feelings and emotions about

death, *to participate* in the decisions of his own treatment, to get *honest* answers, to find himself again through *spirituality*, to die in *dignity* and, maybe the most important issue, *not to die alone*!

ORIGINAL PAPERS

What is expected of a palliative care team?

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Abstract

Objective:
Palliative care tends to be more and more part of the care delivered to patients living with incurable diseases, both during the specific therapy of the disease and when specific therapies are no longer recommended.
Method:
Compared with the early days of palliative care (30 years ago), palliative care teams differentiate their interventions in order to better adapt to the identified needs for care.
Outcomes:
Cancer patients expect mainly efficient symptom control and self-involvement opportunities in decisions regarding the ongoing care from a palliative care team. For HIV/AIDS patients, palliative care teams are looking for the right way to integrate themselves into the local medical culture.
Conclusions:
Proper assessment of specific needs for palliative care of these patients is the right way to ensure the best response and to deliver quality palliative care.

Key words*: palliative care, systematic assessment, HIV*

(Full text in Romanian)

A modern approach to palliative care in HIV-infected children

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Abstract

Objective:
This article describes the ‘state of the art’ for treatment of children with HIV.
Method:
Clinical practice, international guidelines and definitions and literature review are analyzed to present the way children with HIV should be treated.
Outcomes:
The literature clearly indicates the need for an integrative approach in taking care for children with HIV as does experiences in care for these children. The knowledge on palliative care these days offers various solutions to tackle the complex, but common problems which occur in children with HIV.
Adequate solutions include symptom management, prevention, combining curative and palliative care with psychological and social support.
Conclusions:
HIV infection and AIDS-related morbidity and mortality in children require prompt interventions from health care professionals, in terms of antiretroviral treatment (implementation of HAART), as well as other occurring illnesses (HIV-related or not). A holistic approach is recommended, including medical, psychological, social, spiritual, and community care, started as soon as the HIV infection diagnosis is confirmed. Special importance should be paid to symptom alleviation, notably pain relief, to the approach of the HIV-infected child’s family, to the effect of the care on healthcare professionals, and to legal aspects.

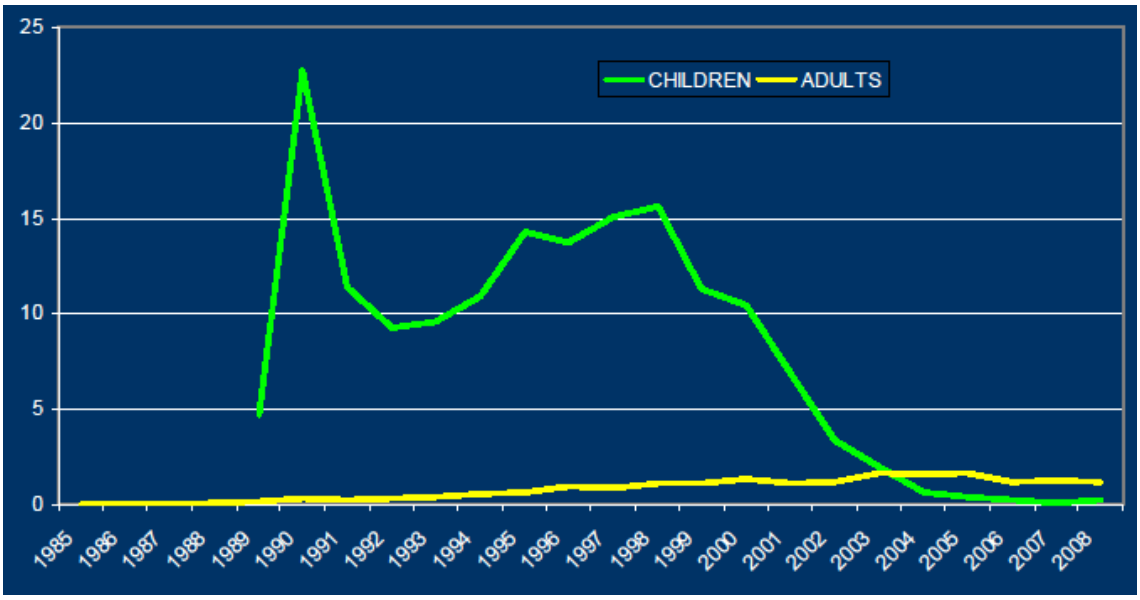
Key words: *palliative care, children, HIV, AIDS, holistic approach*

Introduction

Preventing new HIV infections and decreasing the figures of AIDS-related deaths have been the achievements of recent years, especially in those countries that have implemented complete antiretroviral treatment schedules for HIV-positive patients, together with strategies for preventing both horizontal and vertical transmission of the HIV infection. However, according to the United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) (1), the number of people living with HIV continues to increase, while AIDS-related illnesses remain an important cause for global premature mortality, a situation estimated to continue for the decades to come.

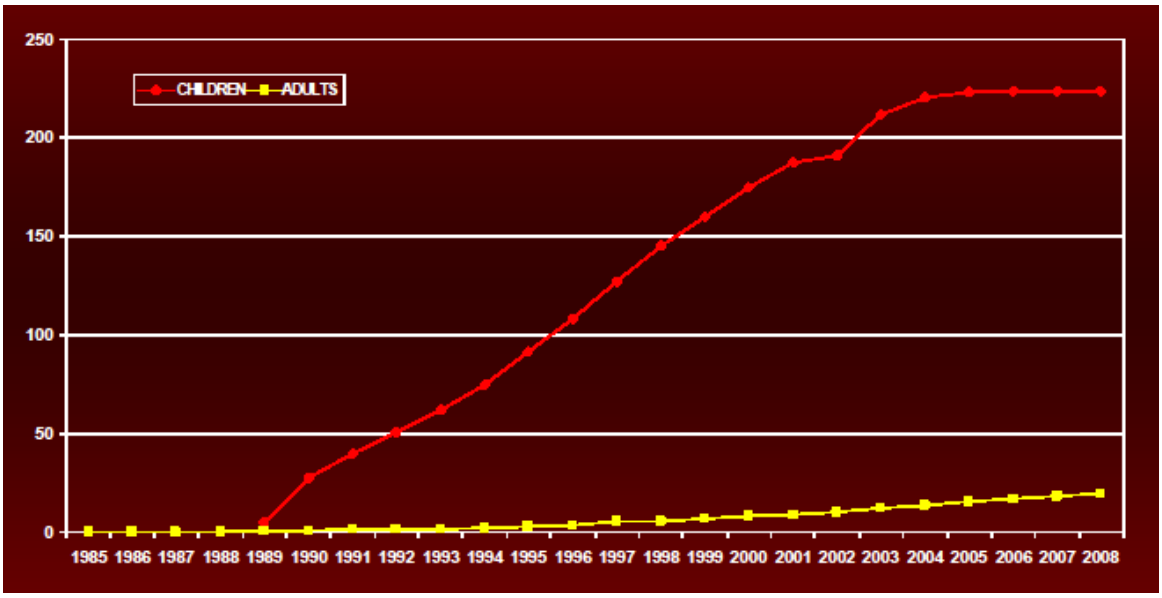
While globally the number of HIV-infected adults has consistently been considerably higher than the number of HIV-infected children, a particular situation was documented in Romania, where up to the year 2001, the incidence of newly diagnosed HIV infections was higher in children (under 14 years old) than in adults (Figure 1).

Figure 1 – Distribution of new AIDS cases in Romania by year of diagnosis and age groups (1985–2008) (2)



This high incidence in children explains the high prevalence (as compared to the prevalence of the HIV infection in adults) currently recorded in Romania (Figure 2).

Figure 2 – Prevalence of AIDS in Romania in adults and children (1985–2008) (29)



The above situation is due to a specific pattern of the transmission of the HIV infection in children. From the first case that has been documented in a Romanian children, in 1989, up to 2008, almost two thirds of the HIV-infected children have acquired the infection in a health care facility, with a further 20% of the total being infected with HIV following blood transfusions (2). The vertical transmission accounted for less than 5% of the reported cases,

although internationally mother-to-child is currently considered to be the main way of transmission of the HIV infection in children.

Diagnostic criteria of HIV infection in children

For children older than 18 months, a positive diagnosis of the HIV infection is established by routine antibody testing (3). A confirmed positive result is a reliable indicator of the HIV infection, although there have been reports of anti-HIV antibodies persisting even longer than 18 months (4).

In infants, the positive diagnosis requires virology tests, primarily HIV-DNA PCR. Testing is recommended in newborns, after 1 month of age, and after 3 months of age. Although false-negative results can occur in newborns, it is widely accepted that sensitivity of the test is very reliable after 1 month of age (4). On the other hand, false-positive results are possible; any PCR positive for HIV-DNA should be repeated immediately.

A whole set of diagnostic criteria has been developed by the WHO for children under 18 months of age, in health care settings where virology testing is not available (5). These criteria include both clinical findings and more affordable laboratory tests (biological markers).

A holistic approach to HIV-infected children care

Once a positive diagnosis for HIV infection is established in children, the main goals of health care include insuring access to preventive, diagnostic, follow-up and support services, and to medical treatment; preventing HIV-related morbidity and mortality; insuring normal growth and development; improving the quality of life for both the HIV-infected children and their families.

Caring for an HIV-infected child must start with staging the infection early after diagnosis. The regular follow-up of growth and development, with usual healthcare interventions (notably vaccinations) will be doubled by thorough search for and prophylaxis of infections, and antiretroviral treatment if necessary. Psychosocial support will be provided to the child, the mother of the child, and the family. The child will be included in the national program for HIV-infected patients. Whenever possible, home-based or community-based care will replace hospitalizations, thus allowing for a better social integration of the child, and for less traumatic treatments for common health problems, while keeping the cost of care under control, avoiding lengthy hospital stays; the benefits should be weighted against the risks, in order to ensure the best standard of care.

Palliative care is defined by WHO as “an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems” (6). Further more, WHO adds to the definition of palliative care for children: “It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease”. (7) Palliative care may play a role not only in improving the quality of life, but also in a better long term outcome. (8) However, hard evidence is scarce, as proven in a recent systematic review from the Cochrane Collaboration, which found that certain settings and models of care may improve patient mortality and other outcomes, although the existing data are not sufficient for more specific conclusions (9).

In HIV-infected patients, we observe important differences in the approach of adults and children, respectively. While in adults the medical care is always the first to be initiated, with palliation added along the way, depending on the progression of the immune depression and

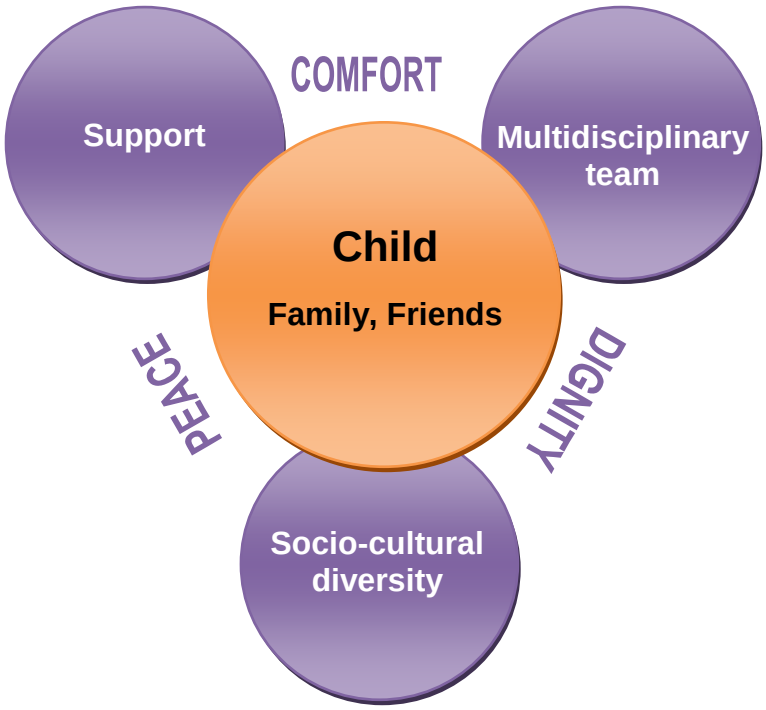
the occurring co morbidities (10), in children palliative care and its components are started immediately after the positive diagnosis, together with the medical treatment (11).

The medication aspects of caring for an HIV-infected child have been extensively approached worldwide, resulting in the large number of guidelines and therapeutic protocols currently in use, continuously updated based on new advances in therapy. Those guidelines are only part of the care, complemented with a palliative approach.

According to the WHO, palliative care: “provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient’s illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness” (6).

Paediatric palliative care takes into consideration the needs of children and their families, integrating all aspects of care and offering a holistic, multidisciplinary approach (12, 13). The whole process of care should be seen as a child and family-centred effort, benefitting from the ongoing collaboration between different healthcare professionals, community and socio-cultural groups, working towards the common goal of achieving patient’s quality of life (Figure 3). An effective HIV care program must be based on respect for patient autonomy and provision of accurate and adequate information, a solid relationship of trust between the care givers and the child and the patients’ family, support of the patient and caregivers in delivering palliative care, integration and respect for cultural values, enhanced quality of life throughout the course of the disease (14).

Figure 3 – An approach to integrative care of HIV-positive children



The health needs of an individual child change over time, depending on the stage of illness and other circumstances. The evolving pattern of needs requires multiple providers, a participatory care plan, and effective mechanisms of communication among all caregivers (5).

There can be described three types of health-related problems in HIV-infected children. Firstly, the normal growth and development needs common in all children, but of particular interest in HIV-infected paediatric patients. Secondly, once the immune suppression occurs and advances, the potential of contracting various infections increases, together with the risk of a bad outcome, thus making both prevention and early detection and treatment a priority. Finally, the third particular type of health-related problems includes the medical conditions associated with the terminal stages of the disease, which relies more on the palliative side of the healthcare approach (15).

Psychological support is an essential component of caring for HIV-infected patients (15), and it consists in establishing a connection with the children and their families in order for them to adequately express and find solutions to their worries, and to plan their life in these circumstances. Children with HIV often see themselves as “different” from uninfected children, and some of their reactions include anxiety, fear of dying, and all sort of privations (external or self imposed).

Symptom alleviation

We emphasize the importance of symptom relief, especially since many pediatric symptoms are often overlooked and sometimes difficult to recognize. The guiding principle in symptomatic relief states that *the right drug* should be given at *the right time*, in *the right dose*, and on *the right route of administration.*

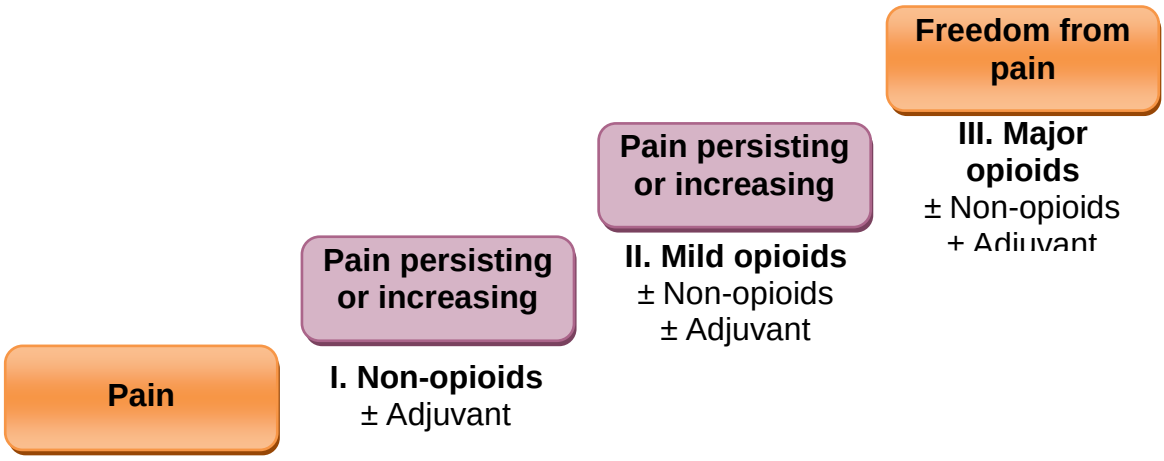
Table 1 – Common specific symptoms, causes, and their management (5)

Symptoms	Causes	Management
Nausea and vomiting	Drugs, gastrointestinal infections, fever	Small frequent feeds, fluids between meals; offer cold foods, eat before taking medications, dry foods, avoid sweet, fatty, salty, or spicy foods.
Sore mouth	Herpes simplex, aphthous ulcers, thrush, gingivitis	Keep mouth clean. Give clear water after each feed. Avoid acidic drinks and hot food. Give sour milk or porridge, soft and mashed. Ice cubes may help; ice cream or yoghurt.
Chronic diarrhea	Infections, malabsorption, malignancies, drug-related	Rehydration, diet modification (e.g. yoghurt rather than fresh milk), micronutrient supplements. Oral morphine can alleviate intractable diarrhea.
Persistent cough, dyspnea	Infections, bronchiectasis	Nebulization with physiotherapy, low-dose morphine
Severe dermatitis	Infections and infestations, hypersensitivity, malignancies	Emollients, antihistamines, antiseptics, topical steroids. Keep nails short to minimize trauma and secondary infection from scratching
Convulsions	Infections and infestations, encephalopathy, malignancies, metabolic disorders	Anticonvulsants, dextrose, mannitol, steroids
Wounds	Infections, pressure, malnutrition	Wound dressing, topic treatment

Pain is a major symptom in children of all ages (including neonates) (16), although recognizing and treating pain is not always seen as a priority. The incidence of pain in HIV-infected children is comparable to that seen in childhood cancer, up to around two thirds of all infected children. (17) A thorough search for signs and potential causes of pain is recommended (18). Depending on the age of the examined child, a series of general signs (pain, fatigue), or specific signs (Table 1) can be reported.

Non-pharmacological interventions are very useful in children, as means of increasing compliance to invasive treatments, or to chemotherapy. In infants and toddlers, distraction methods (such as non-nutritive sucking, or blowing bubbles) are particularly effective in allowing in-depth investigations by relieving the child's anxiety towards the medical staff. This sort of interventions are very good adjuvant to pharmacological treatment.

Figure 4 – WHO's pain relief ladder (19)



Pain will be treated according to the WHO's pain ladder (19): opioids and non-opioids in an escalating order (Figure 4); aspirin (acetylsalicylic acid) is not recommended in children, due to the occurrence risk of the Reye's syndrome. Posology of analgesic drugs in children according to the WHO's ladder is detailed in Table 2.

Adjuvant pharmacological treatments include anxiolytic, antidepressant, anticonvulsive, antihistaminic, and neuroleptic medication (20).

An appropriate pain management strategy should focus on anticipating the pain, whenever possible, rather than relieving the already existing one (21). A constant analgesic level, when necessary, is preferred to the PRN regimen. It is worth mentioning that current Romanian laws and practice regulations provide simplified prescribing requirements and allow for modern pain management, according to the WHO's pain ladder (22, 23). A comprehensive approach to pain in HIV-infected children will take into consideration all potentially aggravating factors that need to be addressed through specific interventions (Table 3).

Terminal care

The common symptoms that need to be addressed in the late stages of the HIV infection include anorexia, dysphagia, diarrhoea, nausea and vomiting, constipation, skin problems, incontinence, dyspnoea, anxiety, sleep problems, asthenia, confusion, terminal agitation.

Table 2 – Use of opioids and non-opioid analgesics in children (30)

Step	Drug	Average dose	Route	Frequency	Maximum daily dose
I. non-opioids	Paracetamol	10-15 mg/kg	PO/PR	Q4-6 h	75 mg/kg
	Ibuprofen	5-10 mg/kg	PO	Q6-8 h	40 mg/kg
	Indomethacin	0.5 mg/kg	PO/PR	Q6 h	4 mg/kg
II. mild opioids	Codeine	0.5-1 mg/kg	IM/SC/PO	Q4-6 h	30 mg (2-6 y) 60 mg
	Hydrocodone	0.135 mg/kg	PO	Q4-6 h	
	Oxycodone	0.05-0.15 mg/kg	PO	Q4-6 h PRN	
III. major opioids	Morphine	Neonates 0.05-0.2 mg/kg Infants&Children 0.2-0.5 mg/kg Infants&Children 0.1-0.2 mg/kg	IM/IV/SC PO IM/IV/SC	Q4 h Q4-6 h PRN Q2-4 h PRN	15 mg/dose
	Meperidine	1-1.5 mg/kg	PO/IM/IV/SC	Q3-4 h PRN	100 mg
	Hydromorphone	Children 0.015 mg/kg Children 0.03-0.08 mg/kg	IV PO	Q4-6 h PRN	
	Fentanyl	1-2 mcg/kg	IV/IM	Q30-60 min PRN	
	Methadone	0.7 mg/kg/24 h divided	PO/SC/IM/IV	Q4-6 h PRN	10 mg/dose

Table 3 – Potentially aggravating factors of pain in HIV-infected children

Aggravating factors	Characteristics
Disease	Quickly progressing, persistent pain; uncontrolled symptoms Longstanding disease/trauma leading to psychological exhaustion Deformity, disability, physical dependence
Patient	Fearing pain, deformity, death Loss of control, independence, dignity, self-esteem Feeling desperation, isolation, anger Culture-related issues
Social	Pre-existing familial problems Failure of social support Insufficiency of available resources
Healthcare providers	Poor communication skills, lack of implication, non-involvement Lack of training in palliative care Lack of education in integrative healthcare Exclusion of the patient and family in decision-making process Lack of cultural deference Exclusion of the spiritual and cultural aspects of care
Treatment	Late diagnosis Multiple treatment failures Unscientific approach to treatment and symptom alleviation

Anorexia is common in the late stages of the disease, and often irreversible. Oral causes should be looked for, and treated if present. Attention will be paid to the fluid intake, in order to avoid dehydration. Various methods can be tried to increase the appetite, and the child should be referred to a nutritionist. In case of **dysphagia**, solid food will be replaced with

liquid or semisolid meals. **Nausea** can be caused by many of the drugs recommended in HIV-infected children, and also by various pathological conditions (increased intracranial pressure, sepsis, uraemia, constipation, anxiety etc.). In case of **diarrhoea**, dehydration must be identified early, and water and electrolytes replacement needs to be considered.

Skin problems are frequent and their aetiology can vary greatly (bacteria, fungi or viruses infections, cancers, eczema, adverse reactions to medication, eschars etc.). The management will need to address both the underlying cause, and the symptoms.

Terminal agitation is the very final stage of the advanced disease. Nevertheless, treatable conditions can mimic terminal agitation, and they need to be addressed promptly: distension of the bladder or rectum, dyspnoea, hypoxia, pain, depression, anxiety, drug withdrawal or side effects etc. Hospices admitting patients for terminal care have well described the "Lazarus phenomenon", where patients walk out a week later, after recovering from an opportunistic infection, or after receiving adequate nutrition (24). Sedatives and anxiolytics are often needed, together with continuous surveillance, physical comfort, emotional and spiritual support for the child and the child's family (25). The cultural and spiritual customs and beliefs for the dying patient should be respected still, at this stage.

Care for caregivers. Legal issues

Caring for an HIV-infected child in terminal stage is both a physical and an emotional challenge. All the caregivers must have access to some form of support. To prevent the occurrence of the burnout syndrome and of the professional exhaustion responsibility will be divided between the various caregivers, and shared with the child's family. The caregivers will be offered emotional and professional support, in environments such as support groups.

There are certain delicate issues in the process of care for an HIV-infected child, such as the patient's right to confidentiality, and terminal care. The former is especially important in children at risk of being stigmatized within the community; precautions are needed to avoid possible exclusion reactions from other entities involved in the educational process of the child. The problems with terminal care consist in the current opinion that symptom relief should progress as the disease advances. In term, this means that higher doses and stronger medication will be required for analgesia in terminally-ill patients, at the risk of a faster approach to the patient's death. Given the medical indications of this pharmaceutical strategy, there is legal and ethical justification for this approach. One other important issue is the attitude in the emergency department when faced with a terminally-ill HIV-infected child. While heroics have no place in these cases, common and aggravating conditions can and must be treated (26).

Teamwork

Healthcare services for an HIV-infected child, in a modern approach, consist of a conjugated effort from a multidisciplinary team, taking into account most aspects of care. Complimentary to the physicians and nurses, the team includes counselling professionals, social workers, physical therapists, nutritionists, home-based care workers etc. The multidisciplinary group is not only a horizontal structure, but also a vertical one, including all levels of specialized care that are or will be accessed during the course of the disease. A special attention will be paid to the basic level of care, whose work has an immediate and sustained impact over the quality of life of HIV-infected children and their families.

Other important issues

The clinical progression of the HIV infection is accelerated in children, and mortality is higher in seropositive infants, in the first year of life (14).

Children cannot care for themselves. The adults in charge with the child's welfare need to be identified and trained in this respect. Family and community-based care should be encouraged and supported, in order to ensure a good adherence to the recommended treatment and an optimal follow-up (14, 15).

Poverty is a key factor that has a negative impact on children with AIDS, primarily by reducing the household ability to cope with the burden of the disease and the additional stress (27,28).

Nutrition and growth are very good indicators of response to treatment, while failure to thrive can be seen as an important sign of clinical deterioration (14).

The concept of palliative care sets the basis for treating terminal stages of HIV/AIDS irrespective of any prediction of the end of the patient's life (29).

Conclusions

HIV infection and AIDS-related morbidity and mortality in children require prompt interventions from the health care system, ranging from medical treatment to psychological support, social integration and family care. A holistic approach is optimal, started as soon as the HIV-infection diagnosis is confirmed. Symptom alleviation must be considered throughout the course of the disease, and not only in the terminal stage, with emphasis on pain relief, often under-diagnosed in HIV-infected children. Practitioners must be aware of the ethical and legal issues implied by their patients' condition.

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Conflict of interest: none

Received: 12 January 2010

Accepted: 7 March 2010

The role of palliative care in HIV infected patients assistance of the Regional Centre Constanța, Romania

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Abstract

Background:
Palliative care is an approach aimed to improve quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care is an essential component of a comprehensive package of care for people living with HIV/AIDS because of the variety of symptoms they may experience. The regional HIV Centre of Constanta is one of the first HIV centres in Romania, where palliative care was introduced in the current medical service. A Palliative Care Department with 5 beds for AIDS patients was realized and operates under supervision of a specialized medical doctor.
Objective:
To highlight the importance of palliative care in medical care of HIV infected patients.
Methods:
Presentation of one year data of patients treated in the Palliative Care Department of Infectious Diseases Hospital Constanta, Romania, in the last year.
Results:
In the last year, 82 patients with HIV/AIDS, were hospitalized in the Palliative Care Department, 36 patients with multiple hospitalizations. The most frequent medical symptoms were pain (26 patients), convulsions (9 patients) and diarrhoea (8 patients), while anxiety was reported by 23 patients and depression by 9 patients. The pathology was dominated by oncology diseases. Fourteen patients deceased during the year.
Conclusions:
Regardless of access to disease-specific treatment, people living with HIV continue to experience symptoms from HIV disease and its co morbidity. Those receiving antiretroviral treatment (ART) may experience adverse effects. Palliative care with disease-specific care is important in the treatment of patients with HIV to promote quality of life and to relieve suffering.

Key words: *HIV, palliative care, counselling, psychotherapy*

(Full text in Romanian)

CLINICAL LESSONS

Aspects of palliative care in child with HIV infection starting from a clinical case

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Abstract

We present the case of an 18 months child with HIV infection, recently diagnosed with vertically transmitted HIV infection, in clinical-immunological stage C3. The child is registered in an Infectious Diseases Institute in Bucharest. After antiviral treatment (HAART- Highly Active Antiretroviral Treatment) introduction the patient developed a severe immune reconstruction inflammatory syndrome (IRIS).

We choose this case to highlight the difficulties in symptom management, especially in small child's pain management, the problems in communication with family members and, in some cases, the difficulty to define a border between palliative and curative care. Although, treatment of a child with IRIS under careful medical surveillance is usually positive, it is possible that unpredictable and fatal complications appear, including sudden death. For professionals it is difficult to assess the prognosis. It is important to recognise the disease's stage as advanced or terminal in time to change curative to supportive therapy or to combine curative and palliative care. However recognition of the evolution of the disease is often not easy for doctors. And for family members it is not easy to accept such developmet. The disease develops irregularly and symptoms may vary. Family members, especially parent of young children, may deny the seriousness of the disease and they lack specific medical knowledge.

Palliative care, however, is complementary and not alternative. Pain and other symptoms must be identified and treated, and the treatment must be complementary to curative therapy as long as possible.

Key words: *HIV infected child, pain, curative-palliative border*

Case report

EM is a 18-months-old female patient, who has been admitted in an Institute of Infectious Disease.
Diagnosis: Symptomatic HIV infection, immuno-clinical stage C3, transmitted vertically; HIV cardiomyopathy with secondary heart failure; Plurifactorial anaemia; Protein-energy malnutrition stage 3; Psychomotor retardation.
Physiological history: firstborn child, delivered spontaneously, at 9 months, weight at birth 3200g, Apgar score 9.
Medical history: EM was hospitalized several times with respiratory and digestive disorders in the regional hospital; she was diagnosed with HIV infection 4 months ago, at the same time with her mother.

Reasons for admittance: prolonged febrile syndrome, protein-caloric malnutrition stage 3 in a child diagnosed with HIV positive.
Clinical examination when admitted: poor general condition, W=5000g, L=68cm, body area = 0.307m^2, fever 39℃ under antithermic treatment, pallid te guments, perioral cyanosis, fluctuating cystic formation, violaceous, 0,5 cm in diameter, in the left scapular area; without lymphadenopathy; respiratory tract – mixed dyspnea, wheesing, productive cough, fine crackles and bronchial coarse rhonchi in both lungs; cardiovasculary system – perioral and extremities' cyanosis, regular heart beats, no shortness of breath, AV=120/min, peripheral pulse present; digestive system – oropharyngeal candidiasis, vomiting, normal stool, supple, acheless abdomen, normal-consistence liver, hepatomegaly, without splenomegaly; anterior fontanelle closed, irritable weeping, hypertonic limbs, with tendency to deflexion; no signs of meningeal irritation, no focal neurological signs; sense organs: reacts to noise, watches. When admitted to hospital her CD4 cell count was 57cells/mm^3, RNA-HIV>10,000,000 copies/ml and after 6 weeks CD4 cell was 352/mm^3, and RNA-HIV=7,450,499 copies/ml.

Prophylactic treatment was initiated with Sulfamethoxazole/Trimethoprim 10mg/kg/day as primary prophylaxis of Pn. jirovecii pneumonia, Azithromycin 20mg/kg/week for prophylaxis of MAC, Izoniazid 5mg/kg/day for prophylaxis of M. tuberculosis; antifungal, antibiotic treatment, with immunoglobulin i.v., glucocorticoid HHC 10mg/kg/day; support treatment consisted of Ondansetron 0.15mg/kg if necessary to prevent vomiting, Acetaminophen (paracetamol) i.v. 15mg/kg/dose and Metamizol pediatric suppository - if necessary, against fever and pain; Ranitidine i.v. 10mg/12hours – as gastric protector.

Evolution in hospital: While hospitalized the child has had several decompensation episodes of heart failure, with favourable evolution under tonicardiac and diuretic treatment. Antiretroviral therapy was started 7 days after her admition, consisting of Zidovudin 16mg/kgx2/day and Lamivudin 4mg/kgx2/day; Lopinavir/Ritonavir 80mg/20mg 1mlx2/day was added as of the 8th day, but was stopped after 2 weeks because of vomiting, anorexia, and stationary weight (day 22).
Beginning the 26th day the general clinical status became altered, fever recurred, the patient presented polypnea with a frequency of 54 respirations /min., diffuse bronchial coarse rhonchi, central cyanosis, AV=140/min, weak crying, no nape stiffness, no focal neurological signs. The biological trials showed leukocytosis with neutrophilia and inflammatory syndrome (VSH=95mm/1hour).

Then the patient presented multi-localized sepsis – pulmonary and cutaneous, for which she was treated with Meropenem and Linezolid, 21 days, having favourable evolution. For the digestive candidiasis she received Fluconazol i.v., the treatment having as result disappearance of candidiasic deposits in the buccal cavity and pharynx and amelioration of digestive tolerance. One month after being admitted to hospital a pneumologist carried out an examination, and, after correlating the clinical and biological data and the cardiopulmonary radiography, the diagnosis of pulmonary tuberculosis was set, initiating treatment with Izoniazid 10mg/kg/day, Rifampicin 10mg/kg/day and Pyrazinamide 25mg/kg/day.

As of the 55th day fever reappeared, associated with important left axillary lymph node. On the 65th day the child EM was transferred to the Pneumology Hospital for special investigations, after which she was to return to the infectious disease clinic.
No pathogenic agent responsible for the presented pathology was found during this whole treatment process.

The diagnosis of IRIS(1) was made on the general aggravation of the clinical status in a HIV-infected patient, immuno-clinical stage C3, three weeks after the introduction of antiretroviral therapy introduction, correlated with increasing CD4 value and decrease in viral replication and presence of infectious and inflammatory syndrome.

Returning to *symptom management*, it must be pointed out that from the 26th day, when the respiratory functional syndrome appeared, to the 60th day, the patient presented dyspnea, with polypnea >40resp/min, shortness of breath associated with episodes of paroxystic dyspnea, treated with HHC 10mg/kg and Theophillin 15 mg; against vomiting, in addition to Odansetron, it was used alternatively Metoclopramide in dose of 0.3mg/kg/day; medication against pain comprised group I WHO antialgics (Acetaminophen and Metamizol); on the 40th day of hospitalization, an abscess of 2/2cm in diameter was found in the left scapula, which was incised in a surgical clinic the next day.

Another problem that came up was the intravenous access, which became more and more difficult during hospitalization, making it necessary at a certain moment to approach a deep venous way by denudation; the central venous access was not possible because of technical problems. The lack of or the difficult approach of a peripheral venous access caused suffering both to the child, because of pain, and to the staff carrying out blood taking or administering the treatment.

Because of the critical general condition, of successive infections, of the digestive candidiasis and probably also medication (as Lopinavir/Ritonavir), it was difficult for the patient to receive food or refused it altogether, his weight being stationary after 5 weeks. This made the physician caring for the patient to decide a naso-gastricfeeding tube insertion. The outcome was positive: the patient put on 1 kg in 3 weeks and began to accept more easily the presence of nurses in the ward, as they administered both the alimentation and most medicines through the tube, minimizing the traumatic interventions quite a lot. Throughout the hospitalization period perfusions for hydro-electrolytic rehydration were applied. We must add that the child's treatment also included hyperproteic products (such as Fresubin or Aminoven), probiotics, digestive enzymes.

Table 1 - Treatments administered according to the type of symptomatology

Symptomatology	Palliative treatment	Curative treatment
pain	-group I antialgics (Acetaminophen, Metamizol)	
dyspnea	- semi-reclining position -treatment for heart failure -oxygen therapy - glucocorticoids (HHC, Dexamethasone); Theophylline	- antibiotic treatment of respiratory infections
fever	-Acetaminophen, Metamizol -hydro-electrolytic rehydration	- antibiotic, antifungal, antiviral treatment
dysphagia	-treatment against pain -topical oral medication	-treatment of digestive candidiasis
vomiting	-Odansetron, Metoclopramide	
anorexia, cachexia	- hyperproteic products (i.v. or p.o.) - hydro-electrolytic rehydration - probiotics - digestive enzymes	-feeding by nasal-gastric probe - antiretroviral treatment

Discussion

I have chosen this case to point out the complexity of both the treatment and care that a HIV/AIDS-infected child at an advanced stage needs and the impact that they have on the familiy and the medical staff.

Taking into account that HIV infection is not curable yet, palliative care in HIV infection is needed. Besides the curative treatment, the symptom management is important, since the quality of life is closely related to it. Ensuring child's comfort is a medical imperative throughout the disease, not only in the terminal phase (2). In the case presented, support treatment and treatment for relief or control of the patient's symptoms are continuously given during hospitalization.

However, it is extremely difficult to evaluate pain in very young patients even for experienced teams. Recognizing pain is already an important step forward, but evaluating, that is quantifying it, is an important stage of the treatment. In order to determine the appropriate therapy it is necessary to find the type of pain (acute or chronic), how it is produced (nociceptive pain, neuropathic, psychogenic – idiopathic, iatrogenic) and pain intensity.

The scales that can be used for evaluating pain in children are Gustave Roussy Pain Scale for Children, but as the patient presents psychomotor retard, more appropriate are DESS (Douleur Enfant San Salvadour) or FLACC (Face Legs Activity Cry Consolability) – evaluation scales approved worldwide. Of course, we can treat pain effectively only when we are very receptive to patient's complaints. Cicely Saunders said that pain must be treated as soon as the patient complains of it, and sometimes we must insist on searching for it, because the patients might think that we do not care about their suffering or that it cannot be resolved (3).

Anticipating pain and other symptoms is an underlying principle of palliative care. Iatrogenic pain, which is caused by the treatments and investigations carried out, is an important component of pain in children. The most frequent interventions are injections, intravenous access and lumbar punctures. Application of Lidocaine/Prilocaine patch one hour before the intervention results in diminished or even absence of pain, comfort of the patient and the medical staff carrying out the procedure. Anticipatory fear and anxiety are common manifestations in pediatrics (4). Despite the effort made by the team to communicate and get close to the child presented above, who has been hospitalized several times, she starts crying every time she sees us and stops only when we go out of the room. Mother's help in diminishing anxiety in such moments is extremely important. At the same time, distracting attention, relaxation techniques, music and hypnosis are successful methods in such situations, but difficult to use in a hospital of acute diseases. Employing MEOPA gas (nitrogen monoxide-oxigen mixture) for small surgical interventions and for dressing, although not so effective with children under 4 years old, reduce anxiety and pain in most cases and prevent anticipatory phobia.

Besides the difficulty in evaluating pain in little children or those with neurological problems, other difficulties in pain management of HIV-infected children arise from parents' negation or minimization of the disease and therefore minimization of pain and child's suffering (5), and also the resistance of medical staff and family to administration of opioids. Although Law 339/2005 allows every Romanian physician who has the right to practise medicine to prescribe opioids, fear of adverse reactions, of addiction, or the idea that "morphine is given only in the terminal phase" limits their utilization very much. Changing the long-established mentality of the population takes time, patience and perseverance. Limited galenical forms for children (lack of preparations in form of drops, syrup or suppository) limit even more their use.

Another problem that arose during EM's hospitalization was the difficulty in getting or lack of peripheral venous access. In palliative care for adults, subcutaneous access (hypodermoclysis) is used and even preferred by some teams due to the fact that it is easy to approach and medication can be easily monitored. In pediatrics, however, the situation is different, subcutaneous and intramuscular ways must be avoided as much as possible, as they can be a source of pain in themselves. Besides, there are few medicines that can be administered subcutaneously, and in our case this would not have permitted, for example, administration of antibiotics for sepsis.

The treatment for dyspnea is done through semi-reclining position, air humidification, oxygen administration, saline nebulization, opioids (systemically or by nebulization), etiologic treatment (e.g. antibiotics, antifungals – for the various infectious causes, diuretic and vasodilatatory – for cardiac causes), bronchodilatatory (nebulization, s.c. or i.v.), glucocorticoids, going as far as mechanical ventilation. Mechanical ventilation can be useful for the patients who have a reversible cause of the respiratory insufficiency, the decision being more difficult in case of a disease in terminal phase. Romanian legislation does not allow (like in other European Union countries) to stop or not to apply those treatments considered unreasonable in the terminal phase of a disease, so the indication regarding mechanical ventilation or its appropriateness cannot be argued either. In the case of our patient, the fact that there was a suspicion of immune reconstitution which was then confirmed, includes her among the patients for whom the palliative treatment is complementary, and the curative one is essential.

The severe condition of the child, with improvements and relapses, induces suffering to the medical staff and the feeling, even if not expressed, of culpability.
The fact that we cannot give a satisfactory answer to the unuttered question of her mother makes us to reconsider our decision and communication ability.

The mother seldom leaves her child or the hospital and only for very short time. Her life has moved into the hospital for about one year, with short breaks, with emergency comebacks and is going on around subjects like fever, vomiting, tests, antibiotics, weight, alimentation. Mother-child relationship is affected by a third character – the hospital. When she speaks, rarely, she says that "there is nothing she can do, she has to bring through this child". Denial of disease? Culpability? Misunderstanding? Or just motherly love, which makes her unable to think of or hear a different variant? Or maybe it is not the disease, she just rejects the idea that it can be deadly? Even more as she herself was recently found to have the same disease...

Cutting edge technique and highly skilled staff can offer the mother a sense of safety, giving her the feeling that here her child is safe from danger, is safe from death. This is what we find out in many families who have HIV-infected children.
But the medical staff interfere and take over part of her "function" as mother; they administer treatments that can cure the baby, but are painful. Hence the ambivalent feelings for the medical team. In such situations, some parents can have feelings of rivalry for the team, can be anxious and claiming, others take on entirely the team's ideas, giving up their own point of view. But our patient's mother belongs to that group of more frail parents who feel they have no longer the right and no longer dare to carry out their duties as parents. All tasks are transferred to the medical team, including feeding – a difficult task. This, as well as child's crying and anxiety in the presence of the medical team increase the risk of isolation of both.

HIV is a chronic disease, with acute attacks. Immune reconstitution syndrome is a difficult episode of the disease, but curable, which prevents the physician from having a pessimistic attitude in front of the mother, despite the serious condition of the child. The rapid development of medicine, permanent emergence of new procedures and new molecules make us reconsider constantly the state of HIV-infected children and start again. At the

university we learned and were prepared to fight against illness – to the end. The human body, object of study, is taken into consideration objectively and treated according to evidence-based medicine. Within palliative care we have the right to look at the children first and offer them the help they need, even though they do not fit in the therapeutical standards(5). This is the complementarity offered by modern palliative medicine. A comprehensive approach to a person is a concept re-established by palliative care (6). It reminds us that our task, as medical professionals is not not only to heal the ill, but also to accompany them.

Providing care is often complicated by presence of disease in other family members, by various social problems, by psychological problems, by financial difficulties.
Setting a border between curative and palliative is impossible most of the time. A few points of reference for the terminal stage of HIV/AIDS would be the development of cancers specific to HIV infection, multiple organ failure, persistence of a high viral load (despite aggressive antiretroviral therapy), with progressive loss of CD4 lymphocytes.

Table 2 - Suggestive death criteria in short time (modified after Selwyn PA)

Decease criteria in short time (7) (under antiretroviral therapy HAART)
Inappropriate response or low tolerance to appropriate HAART treatment
Impossibility to carry out more than two activities a day
Important cognitive clinic handicap
Severe co-morbidities including cancer
Cirrhosis class Child C
Hepatic or renal failure

It is desirable to anticipate the terminal stage of a disease in order to limit as much as possible embarrassing or painful investigations and treatments and to prepare the family for mourning.

Conclusions

Even though the long-term prognosis of patients with HIV/AIDS infection ameliorates, pain, physical or moral, is part of the evolution of a person suffering from this disease and it depends on the medical team to respond to their needs. Introduction in the observation sheet, besides the usual data (temperature, blood pressure, etc.) of a column containing daily evaluation of pain, may lead to sensitizing the medical staff and to a better evaluation and treatment of pain.

HIV/AIDS infection is yet another fatal disease, which comprises suffering, dependence, pain and – still – necessity of transitory or terminal palliative care. Comprehensive approach of these patients' suffering is possible only by cooperation between the different specialties and the whole medical team.

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Conflict of interest: none

Received: 28 December 2009

Accepted: 1 March 2010

Acknowledgements:
{Prof. Dr. Adrian Streinu Cercel, due to whose kindness and under whose direction I carry out my research activity at The Institute of Infectious Diseases „Matei Balş"
Dr. Mariana Mărdărescu, M.D., head of department – Child Immunodepression Clinical Department
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The importance of adherence to treatment in HIV/AIDS: a case study

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Abstract

Objectives:
We are presenting the case of a HIV positive male patient, 21 year old who was first admitted in our department in 2003 when we have established the diagnosis of HIV/AIDS infection stage C3. The patient was born in the Giurgiu County and is one of a group of young children who were infected at birth or in the first year of life through nosocomial mechanism. The patient evolution was as expected in close concordance with his adherence to the antiretroviral therapy.
Discussion:
Analyzing the case evolution in time we discuss the interrelation between the antiretroviral therapy and palliative care. The actual challenge is the correct analysis of both treatment modalities together with a better care for the HIV/AIDS patients. It is important for the HIV care providers to remain sensible throughout the illness evolution and to think always to the patient need for palliative care. The palliative care has much to offer to the HIV/AIDS patients: the increase in the adherence to the HIV therapy, the management of the complex psychosocial needs that they and their families have.

Key words: *HIV/AIDS, ARV therapy, adherence, palliation*

(Full text in Romanian)

MANAGEMENT

Universal precautions in AIDS palliative care

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Abstract

Universal Precautions (UP) represents a concept, which considers that each patient could be a source of different pathogens, which can be transmitted to health care workers (HCW). UP is an aggressive approach, which considers all blood and human body fluids to be potentially infected with HIV, HBV, HCV and other blood born pathogens. Therefore, it’s necessary to apply protective measures, UP ensuring protection of patients, HCW, family, friend and volunteers. Briefly, UP means: washing hands, appropriate use of gloves, face and body protective barriers, needles and syringes, sterilization and disinfection.

UP applies for each medical care activity, for each patient, not only to AIDS patients.
For professional post-exposure (PPE) to blood and human body fluids, the protocol for PPE Prophylaxis shall be followed.

Key words: *universal precautions, palliative care, professional post-exposure prophylaxis, HIV/AIDS*

(Full text in Romanian)

Professional post exposure prophylaxis related to HIV risk of infection

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Abstract

Professional post exposure prophylaxis (PPEP) is part of a large concept regarding Universal Precautions (UP) and represents the unique solution for accidental PPEP.
The risk of infection through professional exposure must be always taken into account related to HIV, HBV, HCV and other pathogens.

Palliative care of AIDS patients suppose to respect all the time UP, since the risk of HIV infections are well-known. For this reason it is mandatory to use the PPEP protocol: incident reporting, evaluation of the exposure severity, primary care, psychological counselling, clinical and serological evaluation for HIV, HBV, HCV, antiretroviral (ARV) prophylaxis, clinical and biological monitoring.

PPEP must be initiated as soon as possible, preferable in the first 72 hours, for 4 weeks, if the tolerance of ARV drugs permits. Evaluation of the exposure severity, the decision of initiation, the ARV schedule and the prophylaxis monitoring belong only to the specialist.

Key words: *palliative care, professional post-exposure prophylaxis, HIV/AIDS, antiretroviral drugs*

(Full text in Romanian)

Opioid treatment of chronic pain in patients with HIV/AIDS – what is different from that of patients with cancer?

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Abstract

New antiretroviral therapies enhance survival for HIV patients and make a shift in pain characteristics: lower overall incidence, but higher proportion of neuropathic pain.

Recommendations for symptomatic pain treatment (including opioids) are no fundamentally different than those for cancer pain. International data show difficulties in pain treatment using opioids in patients with drug abuse history.

For Romania this is not an issue, statistics showing that less than 1% of HIV positive people are inject able drug users. But an important barrier in opioid treatment is the unjustified fear that opioid treatment for pain may be the beginning of the drug abuse.

Key words: *HIV/AIDS related pain, opioids*

(Full text in Romanian)

COMMENTS, DISCUSSION

Adherence in HIV/AIDS treatment

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Abstract

Treatment in HIV infection is a combination of drugs that must continue for years in order to maintain viral suppression. The consequences of loosing control on HIV replication are: reappearance of AIDS symptoms, emerging resistant viruses, increasing the HIV transmission rate.

This particular situation of HIV/AIDS determines the major role of adherence. In this article we describe the most recent aspects concerning HIV treatment adherence, the implication for medical practice and some of the methods that can be used to improve patients’ adherence taking into account the complexity of HIV management.

Many factors can influence the adherence, some of these factors are related to the patients’ social problems, others to the specific type of virus, and again other factors are related to drugs pharmacological aspects or to adverse events associated with antiretroviral therapy.

Key words: *HIV infection, antiretroviral, adherence*

(Full text in Romanian)

Psychological issues in palliative care in patients with HIV/AIDS

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Abstract

The palliative care is an integral approach to deal with the medical, psychological, social and spiritual needs of peoples suffering from serious illness in terminal stages, oncological and non-oncological. The objectives are to contribute to the quality of life of the patient and to support the patients' family. Palliative care is delivered by a multidisciplinary, i.e. doctors, nurses, psychologists and social assistants.

Effective communication between the team and patient/family and sincere collaboration will have a positive influence in illness evolution. Counselling is offered when needed taking into account the treatment or personal moments of the patient. Supporting psychological counselling may is important in all stages of the disease and the care process (diagnose, illness confrontation, treatment, admission, compliance, social integration).

Counselling is directed to cope with difficult situations, to offer sympathy, understanding and encouragement, to support and to express empathy; all of these activities and behaviour intends to find personal solutions for the questions and problems of the patient and his family.

Key words: *HIV*, *palliative care, counselling, psychotherapy*

(Full text in Romanian)

Psychological reference points in palliative care of children with HIV/AIDS

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Abstract

Time, fear and communication are landmarks of palliative care related to HIV/AIDS children. At the same time these are resources and obstacles.

Children with HIV need trust, courage, help and “the right to know”, of course according with their age and beliefs regarding diagnosis. Step by step, started with the disclosure of diagnosis until the final symptoms, the psychotherapeutic intervention – part of palliative care – tries to solve the multiple losses, sometimes irrevocable generated by a severe diagnosis: self history, future, relationships, family and social roles. The child who asks something, maybe difficult questions for adults, often knows the answer already and just requires the permission to talk about this. In such case, the explanations, while being supportive, must be honest, even if answers can not be given completely.

Palliative care for children includes various options to decrease emotional reactions and psychological suffering caused by AIDS, which are very often very intense. Emotional pain, like fear of death, loosing the sense of life and the wish to be alive, could be very real and identically like physical suffering. For this reason palliative care “value” pain!

Pain is a very sensitive and personal experience. Each child will response to pain in his own way and the parents, together with medical and non-medical care staff should keep this in mind.

Key words: *palliative care, HIV/AIDS, psychological reference points, communication*

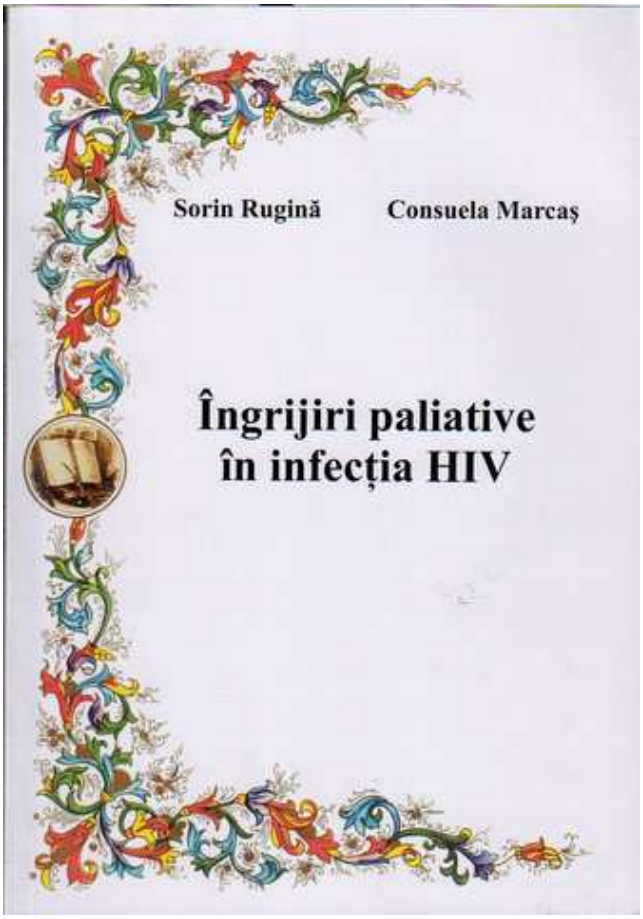
(Full text in Romanian)

NEW PUBLICATION

Palliative care in HIV infection

Rugină S, Marcaş C
Iaşi: Ed.NOEL; 2008

Review



Palliative medicine means to do something beyond the well known "…there is nothing to do…". To limit medical treatment only for the patients who can be cured is a very big mistake. The idea that there is nothing to do, is to easily accepted in the case of major diseases like cancer and HIV/AIDS. HIV infected patients made us "to consider further than the conventional therapy, which at a specified moment is no more important for him, knowing that he will die, to pare this moment by anticipation, than to "oblige" him " to take all life long the therapy". Medical staff involved in palliative care will become more convinced of palliative care, when symptom improvements are noticed. Such experiences may question forcing terminal patients to undergo more investigations and to follow complex treatments, which affect the quality of their life negatively. This is the reason why palliative care has to be used in all fields of medicine in case of terminal diseases.

Palliative care means active care to support medical, psychological, social and spiritual needs of a person suffering of a life-threatening disease (oncological or non-oncological), in a terminal phase with the object to sustain quality of life of the patient and to provide special family support. When dying patients with an incurable disease need the support of the medical staff as do their families. Often the last one is missing and the patient is abandoned.

This book published by the medical staff of Constanta, points out the necessity of palliative care in the assistance of the HIV infected or AIDS suffering patients. The book intends to clarify the concept of palliative medicine in the context of the current assistance to AIDS/HIV infected patients. It is based on the medical staff experience and it illustrates the necessity to respond to the complex problems of these patients. Various experts, including one with competence in palliative care, contributed to this book, which proofs that palliation became a reality in Constanta.

The book deals with the principal aspects of HIV infection from the palliative care perspective. The first 3 chapters present basic elements like the origins of the palliative medicine, definitions and the relationship between HIV and palliative cares.
In the second part, the authors describe applications of palliative care during the various phases of the disease, starting with pain, a principal symptom for which palliative care is necessary, continuing with respiratory, gastrointestinal, dermatological, haematological, urinary, metabolic symptoms and not at least neuropsychiatric symptoms.
The third part of the book is about the palliative medical care in the terminal stage of the disease, the assistance in nutritional problems, in asthenia, fatigability etc., and also about the control of all the symptoms in the last hours of life.
The fourth part presents the clinical significance of all the drugs interactions used in palliative care, reminded in the previous chapters.
The last part is dedicated to the ethical aspects, communication, psycho-emotional support of the family, psychological support of the care medical staff and euthanasia.
The book benefits of a rich documentation and the main bibliography titles are selective inserted.

NEWS

The XVIII International AIDS Conference (AIDS 2010)
Vienna, Austria, from 18 to 23 July 2010

The AIDS 2010 programme will present new scientific knowledge and offer many opportunities for structured dialogue on the major issues facing the global response to HIV. A variety of session types – from abstract-driven presentations to symposia, bridging sessions and plenaries – will meet the needs of various participants. Other related activities, including the Global Village, satellite meetings, exhibitions and affiliated events, will contribute to an exceptional opportunity for professional development and networking.
All of the online tools can be found at http://www.aids2010.org/.

''We are guests of life"

An international conference will be held in Vienna, 15-17 April 2010, entitled 'We are guests of life'. The conference is meant for all people involved in palliative care, including volunteers and family members. The conference language is German.
More information: www.uni-klu.ac.at/pallorg