TIME TO STANDARDIZE OUR PRACTICES OF PAIN MANAGEMENT IN EUROPE

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PAIN IN NON PALLIATIVE SITUATIONS

- In developed contries chronic pain afflicts about 20% of the adult population
  - BUT only 1-2% of adults with chronic pain suffer from cancer
    Pain Clinical Updates, IASP, Volume XII, N°4, September 2004

- Children can suffer from recurrent or persistent pain

  (Perquin and al. Pain. 2000 ; 87 ; 51-58)

  - 25% of the children present chronic pain
  - Location : 22% head
    24,7% abdominal pain
    24,1 % limb pain
    23,5 % back pain

THE MAGNITUDE OF PROBLEM OF PALLIATIVE CARE

Annual mortality rate for children 1-17 years = 1/10 000

Annual morbity rate : 10/10 000

In a population of 250 000 people with about 50 000 children

In one year :

- 5 children are likely to die from life limiting condition
  (2 from cancer, 1 from heart disease, 2 from other conditions)
- 50 would be suffering from a life limiting condition
- 25 of them would need palliative care

CHILDREN WHO MAY NEED PALLIATIVE CARE

Royal College of Paediatrics and Child Health (RCPCH) and the Association for the care of Children with Life threatening and Terminal conditions and their families (ACT)

- Conditions for which curative treatments is possible but may fail
- Diseases where premature death is likely but intensive treatments may prolong good quality life.
- Progressive conditions where treatments is exlusively palliative and may extend for many years.
- Conditions, often with neurological impairment, causing weakness and susceptibility to complications

INCIDENCE of CHRONIC DISEASES and SURVIVAL RATES

	Incidence / 1000 births	Survival Rates
Cystic fibrosis	0.50	70% at 21 years
Spina Bifida	1	45% at 4-8 years
Leukemia	0.03	60%
Congenital Heart Disease	8	52% 15 years
Sickle Cell Disease	0.36	95% at 20 years
Renal Disorders	2	≈ 100%
Muscular Dystrophies	0.14	25% at 20 years

From GORTMAKER SL : Demography of chronic childhood diseases. In N. HOBBS and JM. PERRIN (eds). Issues in the Care of Children with Chronic Illnes. 1985. San Francisco : Jossey-Bass

PAIN IN PALLIATIVE CARE

- CANCER

  - about 80% of the 6-7 million patients dying of cancer annually suffer from pain (Pain Clinical Updates, IASP, Volume XII, N°4, September 2004

  - 89% of children with cancer suffered from of one these 3 symptoms (Wolfe and al. NEJM 2000 ; 342 ; 326-33)
    - pain 56%
    - fatigue 57%
    - dyspnea 50%

  51% of the children presented more than 3 symptoms

- HIV

  - 59% of the children present pain

  Hirschfeld and al. Pediatrics 1996 ; 98 : 449-52

PAIN IN PALLIATIVE CARE

- CYSTIC FIBROSIS : Ravilly et al Pediatrics 1996 ; 98 741-747

  - 84% present important pain
    - thoracic pain 54%
    - head oches 53%
    - back aches 19%
    - abdominal pain 19%

- NEUROMUSCULAR DISEASES , MUSCLE DISORDERS……
  - **Incidence of pain not known : studies to be made**

Inadequate availability of opioid analgesics

Joranson D. and al. Pediatric Pain : Biological and Social Context. Progress in Pain Research and Management. IASP Press, 2003

- Morphine consumption : provides a more realistic picture of patient access to morphine in developing countries

- International Narcotics Control Board conducted a survey in 1995 with the WHO and 65 Governments
- 42 of the 65 governments had issued national policies to improve use of opioids (only 20% related to pain in children)

- Barriers to opioid availability
  - Morphine not sufficiently available
  - Injection forms more available (79%)
  - Slow release (45%)
  - Immediate release or solution (40%)
  - Tablets (29%)

Per Capita Consumption of Morphine (milligrams) in 1999 in different countries

Denmark	**70.7567**	**Portugal**	**2.6719**
Australia	57.0705	**Italy**	**2.3543**
Canada	52.0475	**Lithuania**	**2.1614**
Sweden	**37.2499**	Bulgaria	2.0328
Austria	**36.3185**	Seychelles	1.4750
France	**31.7967**	Belarus	1.3208
Norway	**29.7250**	**Latvia**	**0,9807**
United Stades of America	28.9582	Croatia	0.7398
Switzerland	25.7126	**Greece**	**0.6696**
United Kingdom	**19.9868**	Pepublic of Moldova	0.4306
Germany	**16.8477**	Thailand	0.2868
Ireland	**16.5869**	China	0.1102
Belgium	**11.3191**	India	0.0884
Slovenia	**9.0669**	Nigeria	0.0007
Luxembourg	**8.4149**		
Slovakia	**7.6669**		
Finland	**7.5398**		
Spain	**7.2408**		
Hungary	**7.1883**		
Poland	**6.5055**		
Czech Republic	**5.4825**		
Estonia	**3.9610**		

General situation of Pediatric Palliative Care in Europe

T Dangel J Pain Symptom Manage. 2002, 24 : 160-165

- Data from 24 countries
- Pediatric home care available for all in UK and Belarus
- Inpatient free hospices for children are rare except UK
- Palliative care services provided in pediatric hospitals
- Place of death :
  - Hospital oriented : Belgium, Czech Republic, Greece, Hungary, Italy, Latvia, Netherlands, Poland, Slovakia, Slovenia
  - Balanced : Belarus, Estonia, Germany, Moldova , Switzerland
  - Home oriented : Albania, Bulgaria, France, Romania, UK.

Western Europe (1)

- Germany : 7th rank among european countries for morphine consumption
  - 79 Palliative Care and Hospices for adults
  - Opioids well prescribed
  - No specific education programs
  - 1/3 of the 74 children cancer departments offer palliative home care
  - 4 freestanding hospices for children

Western Europe (2)

- Norway : 5th rank for morphine consumption
  - Focus on the need for palliative care since 1970
  - First university based palliative care unit in Trondheim (1992)
  - Need to develop a curriculum speciality for palliative medecine

- Italy : 20th rank for morphine consumption
  - Pioneering development of pain therapy since 1970 but end of life care hardly acknowledged
  - Obstacles for the use of opioids
  - Need for education and information

Eastern Europe (1)

- Poland :
  - Voluntary hospices and state/public health system
    - 22 freestanding hopices and 50 hospital based hospices
    - 32 hospices provide pediatric palliative care (5 children hospices,and 27 adult hospices
  - Medical education exists : 4 academic palliative medecine sections
  - Opioid availabilty exists : 16th rank for morphine consumption

Eastern Europe (2)

- Craotia :
  - Opioid availabilty satisfactory but 24th position for morphine consumption
  - Regional Hospice Centrum-Zaghreb
  - Develop a curriculum for undergraduate studies

- Romania :
  - One leeding hospice in Brasov
  - 4 pediatric palliative care services : 2 homecare in Brasov, and Oradea, 2 in pediatric oncology wards
  - Opioid prescription needs to be updated and simplified

Eastern Europe (3)

- Lituania : 21th ranking for morphine consumption,
  - No good palliative care and pain management system
  - Opioids availablity is said to be good
  - 2 pain clinics in Vilnius
  - Shortage of healthcare specialists in pain management and palliative care

Eastern Europe (4)

- Slovakia :
  - Oncology treatment centers are sufficient
  - 34 outpatients clinics for pain treatment
  - No speciality of palliative medecine
  - One palliative care ward
  - 12th rank for morphine consumption

- Hungary :
  - 27 organizations provide palliative care
  - 4 palliative care units
  - Opioids available (15th rank)

Concerns for opioid availability

Joranson D. and al. Pediatric Pain : Biological and Social Context. Progress in Pain Research and Management. IASP Press, 2003

- Addiction (72% of the governments)
- Insufficient healthcare professionnels (59%)
- Regulatory restrictions regarding manufacture, distribution, prescribing or dispensing (59%)
- Health professionals concerns about legal sanctions (47%)
- Strict regulatory requirements (38%)

The imperative to evaluate National Policies (1998 WHO publication)

- Importance of adequate governmental and administrative policies
- Governments should institute cancer pain relief programs based on the WHO guidelines (www.whocancerpain.wisc.edu)
- Drug regulatory systems should not prevent children with cancer from receiving drugs for pain relief
- Availability and distribution of opioid analgesics should be reviewed
- Health professionals should report to authorities when drugs are not available

Achieving Balance in National Opioids Control Policy : WHO guidelines for Assessment (2000)

- Define responsability at **every level of chain** of drug distribution(importer, manufacturer, distributor, hospital, pharmacy, hospice, pallaitive care program, physician) so that opioid analgesics are available

- Needs to asses :
  - National policy
  - Annual requirements for opioids
  - Administering the national opioid distribution system

Achieving Balance in Nationak Opioids Control Policy : WHO guidelines for Assessment (2000)

- Using these guidelines :
  - Governments should appoint a comission or task force to prepare a study of national policies
  - Competent authorities should participate in a workshop or strategy session with healthcare professionals to determine the steps needed to follow these guidelines in their country

  - Regional workshops sponsored by the WHO :
    - Pan American Health Organization (2000)
    - Eastern Europe 2002
    - African Countries 2002

IASP-WHO collaboration

- In 2002, the President of IASP, Sir Michael Bond, comitted his term office to increasing IASP's support to developing countries inrecognition of the imbalance in educational and clinical resources between « The West » and those countries
- Offers of :
  - Visiting lectureships and consultancies
  - Translation and publication of IASP publications in various languages
  - Free publications to libraries in currency-restricted countries

Conclusion

- Children's pain continues to be undermanaged and the majority of children who die do not receive « state of the art » end of life care
- There is a need for :
  - Better regulations and reimbursement
  - New initiatives in policy, education and the organization of services

- Can European integration play a crucial role?

- Can management of pain become a rule within the European Community?

WHO's Definition of Palliative Care for Children (1)

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.

- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

- Health providers must evaluate and alleviate a child's physical, psychological, and social distress

WHO's Definition of Palliative Care for Children (2)

- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

- It can be provided in tertiary care facilities, in community health centers and even in children's homes

TIME TO STANDARDIZE OR TO GLOBALIZE

- Children's pain continues to be undermanaged

- The majority of children who die do not receive « state of the art » end of life care

- Lack of policy and program frameworks at all level of governments

Susan Fowler-Kerry (Warsaw, May 2003)