What is it that makes nursing in Paediatric so special?

Eugenia Trigoso
Paediatric Nurses Committee

Istanbul, March 2015
• Introduction

• Age group: what characterizes each group?

• About cancer

• Differences from adults

• Main diagnoses in children

• Late effects

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Introduction

The children are who make nursing in Paediatrics so special! As WHO says, “children are not little adults”.

The EBMT pediatric disease working party (PDWP) defines pediatric patients according to the International Conference of Harmonization as individuals up to 18 years of age.

Child development includes physical, intellectual, social, and emotional changes.

Children grow and mature at very different rates.
Introduction

The children are who make nursing in Paediatrics so special! As WHO says, “children are not little adults”.

⭐ Child development includes physical, intellectual, social, and emotional changes.

⭐ Children grow and mature at very different rates

⭐ HSCT is a commonly used treatment modality for patients with certain types of cancers
⭐ The drawback of this treatment is the risk of severe complications
⭐ Infection, organ dysfunction and
⭐ Late complications: growth retardation, infertility and development of another type of cancer.
Children breathe more air /kg of body weight than adults at rest

Children need more calories and more water per unit of body weight than adults

www.who.int/ceh
Age group: what characterizes each group?

"infants" (birth to 12 months),

To be able to sit alone, without support

Get first tooth

Say mama and dada, using terms appropriately

Understand "NO" and will stop activity in response

Walk while holding on to furniture or other support
Age group: what characterizes each group?

"children" (from 1 up to 10 years),

Preschooler -- 3 to 6 years
Able to draw a circle and square
Balance better, may begin to ride a bicycle
Begin to recognize written words -- reading skills start
Enjoy doing most things independently, without help
Start school
Understand concepts like size and time

School-age child -- 6 to 12 years
Begin gaining skills for team sports (soccer)
Begin to lose "baby" teeth and get permanent teeth
Menarche (first menstrual period) may occur in girls
Peer recognition begins to become important
Age group: what characterizes each group?

"Adolescents" (10 to 19 years)

Physical, mental, emotional, and social changes

Puberty, the process of becoming sexually mature, happens between ages 10 and 14 for girls and ages 12 and 16 for boys

Increased independence from parents

More concerns about body image and clothes

More influence from peers

Greater ability to sense right and wrong

Age group: what characterizes each group?

Each age group is different among them and much more from adults, but common to all of them and different from adults is:

rapid, more pronounced in the first year and adolescence growth, learning and skill acquisition.

So what should we take into consideration?
• children are growing
• children +parents

When a child has a life-threatening disease, the entire family will have adjustments to make so a transplant can involve the entire family

http://www.nlm.nih.gov/medlineplus/puberty.html,
About cancer

Paediatric cancer is still a major public health issue in Europe:

- Leading cause of disease-related death among children and adolescents (1 to 19)
- 15,000 new cases every year in Europe
- 3,000 patients die of cancer each year and it remains the first cause of death by disease in Europe in children older than 1 year
- More than 60 different types of cancer
- The causes of childhood cancer are not well understood.
- Survival rates for most childhood cancers vary widely across cancer types.
- Survival rates for some cancers have improved in recent years, and overall, more than 80 percent of children and adolescents who are diagnosed with cancer live at least 5 years after their diagnosis

Up to 500,000 European citizens are survivors of a paediatric cancer and it is estimated there will be nearly 1 Million by 2020 - 2025
A comparison of pediatric with adult cancers demonstrates differences:

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<th>Origin</th>
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<th>Paediatric</th>
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<td>Most are epithelial</td>
<td>Most are mesenchymal/neural</td>
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<td>Environmental factors</td>
<td>Probably large role</td>
<td>Less important</td>
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<td>Pre-malignant stage</td>
<td>Well-recognized</td>
<td>Rarely identifiable</td>
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<td>Screening and effective preventive strategies</td>
<td>Major impact</td>
<td>Minimal impact</td>
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<td>Majority of diagnosed</td>
<td>Die of their disease</td>
<td>Expected to be cured</td>
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https://www.cure4kids.org/ums/home/seminars/seminars_list/seminar_detail/?ppts_id=822
### Main diagnoses

<table>
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<tr>
<th>Non solid tumours</th>
<th>Solid tumours</th>
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<tr>
<td>• Acute myeloid leukaemia</td>
<td>• Neuroblastoma (high risk &gt; CR1)</td>
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<td>• Acute lymphoblastic leukaemia</td>
<td>• Brain tumours, medulloblastoma and high-grade gliomas responsive to chemotherapy in an attempt to avoid or postpone radiotherapy.</td>
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<td>• Myelodysplastic syndromes</td>
<td>• Soft tissue sarcoma: stage IV or in responding relapse.</td>
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<td>• Chronic myeloproliferative disorders</td>
<td>• Germ cell tumours: after a relapse or with progressive disease.</td>
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<td>• Lymphomas</td>
<td>• Wilms' tumour: relapse.</td>
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<td>• Primary immunodeficiency diseases</td>
<td>• Osteogenic sarcoma: the value of HSCT is not yet clear.</td>
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**Generally, allogeneic HSCT cannot be recommended in children with solid tumours.**

**Allogeneic HSCT may be undertaken in the context of a clinical protocol in specialized centres.**
Outcomes:

**Key events** occur at varying times post-HSCT:

- Neutrophil and platelet engraftment (days 7–45)
- Acute GvHD (aGvHD) (days 4–100)
- Relapse/Progression (anytime after day 0)
- Death
- Chronic GvHD (cGvHD) (days 100 onwards).

The EBMT Handbook – Hematopoietic Stem Cell Transplantation
Late effects

- 20% to 40% of survivors experience long-term side-effects which may be severe and affect their daily life.
- Late effects of treatment are becoming a significant issue in both adult and pediatric cancer survivors.
- Late effects in childhood cancer survivors are both physical and emotional.
- Late effects in childhood cancer survivors may affect the following:
  - Organs, tissues, and body function
  - Growth and development.
  - Mood, feelings, and actions.
  - Thinking, learning, and memory.
  - Social and psychological adjustment
  - Risk of second cancer

Late effects: GvHD

- Young children have been shown to be more sensitive than older ones to the adverse late effects of SCT, at least regarding growth and neuro-cognitive functions.

- Limitations in physical performance.

- Increased coordination problems and muscle weakness compared with healthy siblings.

- Decreased growth hormone secretion.

- Combined physical or psychosocial effects.
Late effects:
Serious effects related to treatment involving the central nervous system in childhood cancer survivors are cognitive impairment, behavioural adjustment problems, and long-term educational and vocational difficulties.

LEARNING DIFFICULTIES
- Handwriting
- Spelling
- Reading and comprehension
- Understanding math facts and concepts
- Difficulty in sequencing
- Auditory or visual processing
- Attention deficits
- Short-term memory and information retrieval
- Planning and organizational skills
- Social maturity and skills
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Research

Is well known the general lack of clinical trials focused on screening and preventive practices among HCT recipients and the need for more research in this area.

... improvement in survival for children has been achieved because of treatment advances that were studied and proved to be effective in clinical trials, which is the way to increase the cure rate and the quality of cure of children with cancer (SIOPE).
Research

On 2nd April 2014 the Clinical Trials Regulation (CTR) has been adopted by the European Parliament (594 votes in favour, 17 against and 13 abstentions).

multinational clinical trials.......for children and adolescents..... are vital (SIOPE)

the high proportion of anti-cancer ‘off label’ drugs used in the paediatric age group (due to the lack of appropriately licensed drugs)

here is a current lack of co-ordination and a significant duplication of efforts and costs in multinational trials across Europe
Research: AYA
Special mention should be made in AYA: AYA patients undergoing HSCT present a very unique perspective, circumstances, medical, psychological and social issues requiring a diligent workup, care and follow-up.

Adolescents and young adults (AYAs) are a very unique subset of our population journeying through a dynamic stage of their lives. This age group often remains understudied as a separate entity because they are commonly lumped into either paediatric or adult subgroups.
Abstract

BACKGROUND: Adolescents and young adults (AYAs) are a very unique subset of our population journeying through a dynamic stage of their lives. This age group often remains understudied as a separate entity because they are commonly lumped into either pediatric or adult subgroups.

METHODS: Here we review acute and chronic issues surrounding hematopoietic stem cell transplantation (HSCT) with a focus on the AYA age group.

RESULTS: HSCT is a commonly used treatment modality for patients with certain types of cancers. AYA patients undergoing HSCT present a very unique perspective, circumstances, medical, psychological and social issues requiring a diligent workup, care and follow-up.

CONCLUSION: The medical care of these patients should be approached in a multidisciplinary method involving the patient, caregivers, physicians, psychologists and social workers.

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PMID: 25228557 [PubMed - indexed for MEDLINE]
Training

The care of these patients should be approached in a **multidisciplinary team** and method involving the patients, family, caregivers, physicians, psychologists and social workers.

It has been demonstrated that survival for children with cancer is more likely if they are diagnosed and treated by an expert team of doctors, nurses, and other specialists working within a specialized unit.

**JACIE Standards:**

B3.7.2 Clinical Programs treating pediatric patients shall have nurses formally **trained** and experienced in the management of pediatric patients receiving cellular therapy.
Training

Such a unit must include trained medical and diagnostic staff, experienced nurses, patient and family support in the form of psychologists, social workers and teachers and the team must be available at all times. In particular, paediatric surgeons, neurosurgeons, anaesthetists, pathologists, specialist nurses, radiotherapy facilities and blood product support must be immediately available with the objective of diagnosing the patient accurately and allowing prompt initiation of appropriate therapy to reduce toxicity and complications as far as possible. (SIOPE -STANDARD)
Patient Family Centered Care

“At the heart of patient family-centered care is the belief that health care staff and the family are partners, working together to best meet the needs of the child”

http://www.stjude.org/

“Parents play a critical role in supporting their child to overcome cancer and need to be supported, with appropriate facilities available to them at the treatment unit. They need to fulfil the role of ‘partners’ in the treatment process of their child”

SIOPE -STANDARDS
General lesson from EBMT data

It was not until 2012 when survey data on the number of paediatric transplants were collected – performed in either dedicated paediatric transplant centres or in centres performing transplants in both adults (>18 years of age at transplant) and paediatrics.

A total of 4,041 transplants – 2,877 (71%) allogeneic and 1,164 (29%) autologous – were reported in patients under the age of 18. An additional 56 (25 allogeneic and 31 autologous) patients >18 years at the time of transplant were reported by 21 of the dedicated pediatric centers

Overall, 118 (18%) centers performed transplants on both adult and pediatric patients; 109 (16%) centers were dedicated pediatric transplant centers; and 434 (66%) centers performed transplants on adults only (29,581 transplants; 11,263 allogeneic and 18,318 autologous).
General lesson from EBMT data

The proportion of autologous to allogeneic HSCT is different in pediatrics (29% autologous) compared with adults (62% autologous), and is mainly used for treating solid tumors.

The pediatric population has continued to represent ~20% of the entire population and is somewhat out of proportion to the number of adult patients in this population.

Also this population, although a minority, is still a significant minority that includes a number of unique diagnoses such as the hemoglobinopathies, immune deficiencies, immune dysregulation and metabolic diseases, all of which are not common or present at all in the adult HSCT population.
Table 1. Numbers of hematopoietic SCTs in Europe in 2012 by indication, donor type and stem cell source.

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<td>Abbreviations: id = identical; HLA/MPN = myelodysplastic syndromes; SAA = severe aplastic anemia; BM = bone marrow; PBPC = peripheral blood progenitor cells; Cord = cord blood.</td>
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Pediatric transplants: 1570, 4236, 58, 445, 766, 6, 7, 39, 1727, 1454, 6076, 694, 8224, 176, 22, 2858, 6, 1521, 22, 1058, 5.
Absolute numbers and relative proportions of indications for pediatric HSCT in the 109 dedicated centers in Europe in 2012:

(A) Proportions of pediatric disease indications for an allogeneic HSCT in Europe in 2012.

(B) Proportions of pediatric disease indications for an autologous HSCT in Europe in 2012.

Bone Marrow Transplantation (2014) 49, 744–750; doi:10.1038/bmt.2014.55
General lesson from EBMT data

- There is a decrease in transplant-related mortality according to the year of transplant (before and after 1992) and the type of HDT regimen.
- As a rule, first-line high-risk patients fare significantly better than relapse patients.
- Age at HDT/HSCT has to be considered for outcome predictions: adolescent age is generally associated with inferior survival rates.
Comments:

Children are not little adults

**Training** and education of all health professionals taking care of children and adolescents with cancer are mandatory.

**The care** of these patients should be approached in a **multidisciplinary team** and method involving the patients, family, caregivers, physicians, psychologists, data managers, social workers.

**Data management** and safety reporting of the therapeutic programme implemented is vital, and appropriately-trained medical staff is required to carry this out. (SIOPE- STANDARDS)
FREQUENTLY ASKED QUESTIONS
THANKS
GRACIAS
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