Inspiring others through the lessons learnt in developing CPC nationwide

Ana Lacerda, MD, MSc Pall Care
Palliative Care MSc

This is a multi-professional course, jointly developed by King’s College London and St Christopher’s Hospice and specifically designed to appeal to leaders of palliative and end of life care. The aim of the course is to develop the skills necessary to appraise research and evidence based care, and to improve clinical practice and lead services.

We support the finest education in palliative care for doctors, nurses and other professionals. One of our priorities is to create opportunities for masters, doctoral, post-doctoral and travel fellowships. These fellowships meet the need to develop future leaders of palliative care throughout the globe and to improve care, research and education through better international exchange of ideas and easing the crossing of cultural barriers.
Don’t be afraid to **step out** of your comfort zone
Paediatric Palliative Care – reflections on current challenges and suggestions for development in Portugal.

Word count: 5078

(excluding foreword, free standing citations, tables, figures, footnotes, appendices, references)
Fig. 2. Levels of pediatric palliative care provision around the world.
Proposal

Literature & International review

Needs assessment (estimates)

PESTLE
- political
- economical
- social
- technological
- legal
- environmental

Soft Systems
- costumers
- actors
- transformation process
- world view
- owners
- environment

National analysis
1. Organization of a national workshop, with relevant stakeholders (table VIII) to:
   1.1. establish directions for service development;
   1.2. elaborate a national policy recommending to:
      1.2.1. develop PPC provision, incorporating bereavement support, for all eligible diagnoses and including neonates and children with disabilities;
      1.2.2. foster initiatives to raise PPC awareness (primary care, general public, schools, local communities);
      1.2.3. incorporate PPC in healthcare providers undergraduate curricula;
      1.2.4. enhance social and economic benefits for families;
   1.3. nominate a national taskforce.

2.2.4. design common frameworks and tools:
   2.2.4.1. identification, referral process, admission criteria;
   2.2.4.2. registries, care pathways, care plans;
   2.2.4.3. outcome measures and key performance indicators;
Lacerda et al: *PPC and death in children with cancer - experience of a local programme*

1st European Congress of PPC, Rome, 2012
Do you know? 

And do you have muscle / email?
Portuguese Society of Pediatrics

Portuguese Association of Palliative Care

Directorate-General of Health
National Child Health Program
National School Health Program
Taskforce of Continued and Palliative Care
Portuguese Society of Pediatrics
(February 2013)

Paediatrics  Medicine  Nursing
Neonatology  Primary care  Intensive care

Ana Lacerda  Joana Mendes  Eulália Calado  Graça Oliveira

Pediatric Taskforce
Portuguese Association of Palliative Care
(April 2013)

Paediatrics  Medicine  Neonatology  Nursing  Palliative care  Psychology  Primary care  Social service

Ana Lacerda  Joana Mendes  Sílvia Ramos  Susana Corte-Real  Helena Salazar

Be **bold** and **daring**

Use all your connections (it’s all about relationships!)

Prepare **meaningful** and well supported presentations

Put on a **smile**
2013

February: Taskforce, Portuguese Society of Paediatrics

March: meeting with National Commission for Maternal and Child Health

April: Taskforce, Portuguese Association of Palliative Care

June: Stakeholders meeting: PPC – a reflexion: what will happen in Portugal?

October: PG Diploma CPC

Meeting’s Report: 24 pages
2014

June: CPC report commissioned by the Secretary of State of Health

September: Taskforce, Continued Care, Central Administration of Health Systems

October: meeting Caring for the child and young adult with palliative care needs: the family’s and the professionals’ views.
Gather an **eclectic** group of people who share your **passion**

(and if they are nice and know how to make cookies, the better!)
Cause and Place of Death of Children and Adolescents in Portugal (1987-2011) - an Epidemiological Study

Research Project
MSc in Palliative Care

January 2014

Student 1220171
Word count: 14,985
Effective collaboration between education and training of all healthcare providers caring for children with PC needs.

Furthering of paediatric homecare.

Reorganization of existing paediatric facilities.

Effective collaboration between settings.

4 Governance Principles

Education and training of all healthcare providers caring for children with PC needs.

Furthering of paediatric homecare.

Reorganization of existing paediatric facilities.

Effective collaboration between settings.

193 pages…**but:** executive summary & each chapter (3) with a 2 page bullet summary.
2015

www.cuidandojuntos.org.pt

Caregivers’ booklet

Website

Publication of CPC report

Optional CPC module for 5th year med students

1st Portuguese CPC Meeting
2nd Friday in October
(PC month)
“It changed my view of Medicine”

Implementing a Multidisciplinary Undergraduate Course on Pediatric Palliative Care for Medical Students

A Lacerda, J Mendes, MJ Moura, E Calado, S Ramos, M Paiva, D Ribeiro, M Miranda
Lots and lots of CPC education...

lectures /... / basic courses (24h) / post graduation (124h)

pediatrics, neonatology, palliative care, primary care

medicine, nursing, therapies, social service, psychology,...

pre / post graduate
18º Congresso Nacional de Pediatria
25 – 27 Out 2017
Centro de Congresses
Alfândega do Porto

ESCOLA DE PEDIATRIA
CUIDADOS PALLIATIVOS PEDIÁTRICOS

21 de setembro (sexta-feira)
13h00 - Princípios e conceitos básicos
19h00 - Anestesia e Intervenção
19h45 - Exames de imagem
20h45 - Treinamento nos cuidados paliativos
22h00 - Reunião dos participantes

22 de setembro (sábado)
09h00 - Comunicação com o criança e família
10h00 - Intervenção
11h00 - Exames de imagem
12h00 - Treinamento nos cuidados paliativos
13h00 - Reunião dos participantes

IX Congresso Nacional
CUIDADOS PALLIATIVOS
Fundação Dr. António Cupertino de Miranda, Porto
25-27 outubro 2018
PREPARAR O FUTURO,
NOVAS SOLUÇÕES

#APCP18
Exhibitions whenever possible...

We did the Portuguese subtitles!
Start spreading **the word**...

Prepare **crisp** and **realistic** reports

Target **all** involved (families included…)

Involve **everyone** (stakeholders include families…)

**Diversify** your educational offer

Give “your” people opportunities to **grow** and **shine**
Don’t be afraid to **reach out** to people you don’t know or never spoke to
Family story

Key concepts

Pediatrics
Palliative Care
Ministry of Health
Gulbenkian Foundation
International Children’s Palliative Care Network
Key concepts

National developments

Available education

Social benefits
Penso que o mais importante na questão dos cuidados a prestar à Constança tem sido a preparação e o conforto, dela e nosso, claro. Refiro-me a saber a que fazer, como fazer e quando fazer. A formação prévia e a aceitação de cada nova etapa dá-nos uma certa serenidade para abraçar os desafios (que são permanentes) e transmitir à Constança - e ao seu irmão - que estamos a fazer tudo o que está ao nosso alcance para que ela se sinta o melhor possível consigo e para que todos possamos aproveitar o melhor de cada um durante este tempo.

Inês, mãe da Constança, portadora de doença neurodegenerativa
Paediatric Palliative Care
maximizing the wellbeing of...

Society
Family
Child
Paediatric Palliative Care
WHO, 2014 – Integration in the healthcare continuum

Tx of baseline illness
(e.g. chemotherapy)

Active medical Tx
(e.g. infections, fractures)

Symptom control
Psychological, social and spiritual support

Bereavement care

Diagnosis
Death

Support

End of life
Terminal

Adapted from Woodruff, 2004
Integration
Continuity
Paediatric chronic illness trajectories

<table>
<thead>
<tr>
<th>ACT I</th>
<th>ACT II</th>
<th>ACT III</th>
<th>ACT IV</th>
</tr>
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<tbody>
<tr>
<td>Normality</td>
<td>conditions where curative treatment may be feasible but can fail</td>
<td>conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible</td>
<td>progressive conditions without curative treatment options in which treatment is exclusively palliative</td>
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Time (years)

Hain & Wallace Paed & Child Health 2008;18(3):141
(adapted with permission)
Figure 4: Different levels of palliative care services which should form the basis of a children’s palliative care service

Children and young people with palliative care needs and their families can access the services they need according to the different stage of the child’s condition.

- **Specialist Palliative Care Services**
  - Tertiary specialist paediatric care and symptom control.

- **Core Palliative Care Services**
  - These form the majority of services required by children and young people with palliative care needs and their families, e.g. community nursing teams, hospices, bereavement services, sibling support.

- **Universal Services**
  - The foundations for a good palliative care service includes services which are available to all children and young people, e.g. GPs, education, playgroups.

A key worker will be responsible for ensuring joined-up and co-ordinated service provision.

Craft & Killen, 2007
Early integration of CPC

Kaye et al, Pediatr Blood Cancer 2016; 63:593
IMPaCCT: Normas para a prática de Cuidados Paliativos Pediátricos na Europa

Documento elaborado pelo Grupo de Peritos da Task Force da EAPC (European Association for Palliative Care) para Cuidados Paliativos Pediátricos (crianças e adolescentes)

Tradução: Manuel Luis Vila Copeiras, RN, MSc
Revisão por: Joana Mendes, RN, MS and Maria João Santos, RN, MS
Palliative care for infants, children and young people – the facts (2009)
A family companion to the TfSL core care pathway for children with life-limiting and life-threatening conditions (2014)
CARTA DA CRIANÇA COM NECESSIDADES PALIATIVAS

AS CRIANÇAS COM DOENÇAS CRÔNICAS COMPLEXAS, LIMITANTES OU AMEAÇADORAS DA VIDA, E AS SUAS FAMÍLIAS, DEVEM ESPERAR DOS PROFISSIONAIS DE SAÚDE...

... SEREM TRATADAS COM RESPEITO E DIGNIDADE.
... UMA COMUNICAÇÃO ABERTA E HONESTA.
... SEREM SEMPRE OUVIDAS E ENCORAJADAS A FALAR SOBRE OS SEUS DESEJOS, ESCOLHAS E PREFERÊNCIAS.
... QUE EM TODAS AS FASES DE PRESTAÇÃO DE CUIDADOS, DESDE O DIAGNÓSTICO ATÉ À MORTE E LUTO, SEJA FORNECIDA INFORMAÇÃO RELEVANTE E CLARA.
... A ELABORAÇÃO DE UM PLANO DE CUIDADOS INDIVIDUALIZADO, BASEADO NAS NECESSIDADES ÚNICAS DE CADA CASO.
... QUE A EQUIPA TRABALHE COM O OBJETIVO DE APOIAR A FAMÍLIA.
... QUE, SEMPRE QUE POSSÍVEL, PRESTEM CUIDADOS NO LOCAL PREFERIDO PELA FAMÍLIA - CASA, CENTRO DE SAÚDE, HOSPITAL OU OUTRA UNIDADE DE INTERNAMENTO.
... ORIENTAÇÃO EM PNL, COACHING E ESTRATÉGIA, SEMPRE QUE NECESSÁRIO E DESEJADO.
... A OPORTUNIDADE DE TER ACESSO À EDUCAÇÃO E EMPREGO ADEQUADOS.
... QUE OS DESEJOS, ESCOLHAS E PREFERÊNCIAS RELATIVOS AOS CUIDADOS DE FIM DE VIDA SEJAM DISCUTIDOS E PLANEJADOS ATENTIVAMENTE.
... QUE O APOIO SE APLIQUE A TODOS OS QUE SE RELACIONAM HABITUALMENTE COM A CRIANÇA (FAMÍLIA, AMIGOS, COLEGAS DE ESCOLA, ETC.).

Charter of the rights of the dying child - the Trieste Charter (2014)
Religions of the world charter for children’s palliative care (2015)
Estão preocupados com o vosso filho?

UM GUIA PARA APOIAR FAMÍLIAS DE CRIANÇAS COM NECESIDADES COMPLEXAS E OS PROFISSIONAIS QUE DELAS CUIDAM

Are you worried about your child? (2018)
Prepare concise, attractive & accessible information*

Ask permission to translate brilliant documents!

* if possible print out leaflets / brochures for families
  always make these pdfs widely available
January: Pediatric Taskforce (MoH continued and PC reform)

January: Portuguese Observatory of Pall Care

June: Opening of first pediatric unit

October: 20 scholarships for PG in CPC

Fostering epidemiological research for needs assessment
Hospital CPC Teams


H. S. Francisco Xavier - Neonatology

H. D. Estefânea – Children’s Hospital Lisboa
H. St. Marta (Cardiology)

Oncology Institute – Lisbon
Oncology Institute – Porto
CH Porto
ULS Matosinhos

H. St. Maria – Pediatrics
H. St. Maria – Neonatology
CHUC – Children’s Hospital Coimbra
2017

Creation of the Ethics & Pall Care Group of the Portuguese Society of Neonatology

Comissão de Ética e Cuidados Paliativos
Lincoln Justo da Silva (Lisboa)
Graça Roldão (Lisboa)
Joana Mendes (Lisboa)
Cármen Carvalho (Porto)

Living efficiently:
www.vivereficiente.pt
2018

March: national policy - **mandatory** CPC hospital teams

May: 2nd National CPC Meeting

Further development of pediatric homecare

College of Pediatrics: inclusion of CPC curricula in specialty training

...?: national policy on pediatric integrated care

nomination of CPC national and regional coordinators
Applaud government requests but be prepared to...

...wait
...be given short notices
...squiggle a bit
...repeat yourself endlessly

...wait some more
Profile of Children’s Palliative Care in Portugal raised through the VIII National Palliative Care Conference

Government in Portugal mandates the creation of paediatric palliative care teams in all hospitals
Important Research from the USA replicated in Portugal

Author: Dr. Joana Mendes
19 August 2013
Research

Workshop on neonatal palliative care held in Portugal

Author: Dr. Joana Mendes
26 May 2016
News | Education

Perinatal Palliative Care on the agenda of the Portuguese Neonatal Society in Portugal

Author: Dr. Joana Mendes
03 October 2017
News | Education
Give feedback & make people / institutions proud of what everyone has achieved together
Portugal – level 3 since 2015 = evidence of localized provision, with available training (until February 2013 – level 0 = no recognized provision)
<table>
<thead>
<tr>
<th>TEMA</th>
<th>INTERVENIENTES</th>
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<tr>
<td>12:15H Cuidados paliativos pediátricos em Portugal: a construção de um caminho para e com as</td>
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**REPÚBLICA PORTUGUESA**

**SAÚDE**

**PROGRAMA | CRIANÇAS E JOVENS PROTAGONISTAS DA SUA SAÚDE**

01 de junho de 2018 | Teatro Thalia - Estrada das Laranjeiras, 211 Lisboa
(Coordenadas GPS: 38° 44' 42.95" N 10° 9' 76" W)

**crianças**

O que os pais de Crianças com doenças complexas precisam que os Profissionais de Saúde compreendam

**Paula Duarte | Comissão Regional da Saúde da Mulher, da Criança e do Adolescente**

**A Experiência d’O kastelo**

**Teresa Folha | Instituto Nacional de Saúde Doutor Ricardo Jorge**
Don’t...

...be afraid
...think you can’t / don’t have a voice
...think that something is too small to have an impact
Obrigada! 

Aua

alacerda@ipolisboa.min-saude.pt