Global Palliative Care - working towards sustainability

PCW Palliative Care Works

Global Palliative Care working towards sustainability: **Achievements and** Challenges

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Paradigm of Palliative and End of Life care

Global Movement for palliative care

> National Architecture

Service infrastructure

family and community -

People

You and Me

Palliative care.....

- Never before, has there been such a global recognition for the need for palliative care and commitment to providing it.
- In the UK there has been both negative and positive media focus on palliative care
- WHO Technical Advisory Group
- Lancet Commission on Palliative Care
- International organisations:
 - International Children's Palliative Care Network (ICPCN)
 - International Association of Hospice and Palliative Care (IAHPC)
 - Worldwide Hospice & Palliative Care Association (WHPCA)

World Health Assembly



- Resolution on PC passed at the 67th WHA in Geneva in May 2014
- Strengthening of PC as a component of integrated treatment throughout the life course

The Resolution



- Wide and all encompassing
- Sets out definition of PC and the need
- Recognises PC is fundamental in improving QoL and is a human right
- Affirms the need for access to essential medications, including opioids
- Acknowledges PC is an ethical responsibility for health systems and providers
- Recognises need for PC across age groups, disease groups, models etc
- Welcomes the inclusion of PC in the definition of universal health coverage and the need for integrated PC.

 It urges member states to "develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes." (WHA 2014 p3)

Moving forward....

 Member states are urged to 'implement the resolution' and to 'tear down barriers to PC and end unnecessary suffering' (WPCA 2014)



In order to achieve this
 it must be sustainable

So what do we mean by sustainability?

 Sustain can mean "maintain", "support" or "endure" Sustainability – the ability to be sustained, supported, upheld or confirmed

 Sustainability is defined as a requirement of our generation to manage the resource base such that the average quality of life that we ensure ourselves can potentially be shared by all future generations. ... Development is sustainable if it involves a non-decreasing average quality of life.

[Geir B. Asheim, "Sustainability," The World Bank, 1994]

Sustainability in healthcare?

- Sustainability could be defined as an ability or capacity of something to be maintained or to sustain itself. If an activity is said to be sustainable, it should be able to continue forever. (Landlearn NSW)
- Emerging approaches to health, care and wellbeing need to be increasingly environmentally sustainable, financially sustainable and also make far smarter use of our ... social and human capital.... It also needs to help build resilience into people, families and communities..... Thus depending on supporting effective networks within communities, locally and globally, that enable the health system to provide support and services with people rather than just to people. (NHS Sustainability strategy 2014)

Building a sustainability solution



Four key steps:

- 1. Set strategy and policy
- 2. Build information and analytical platform to measure and monitor programmes
- Develop programmes and projects to accomplish the strategy
- Develop communications to engage with stakeholders

(Smith 2010)

So what does that mean for us when increasing global access to palliative care?



The need e.g. Cancer deaths



- 8 million people died from Cancer in 2010, 38% more than 20 years ago
- 15.1% of all deaths due to cancer

(Lozano et al 2012)

In sub-Saharan Africa

- Rates expected to grow by 400% over 50 years
- By 2020 70% of new cancer cases will be in the developing world
- Late presentation (80% advanced & incurable)
- Inadequate diagnostic and treatment facilities
 - E.g. radiotherapy



Those needing palliative care at end-of-life

- 54.6 million deaths in 2011
- 66% due to NCDs
- >29 million died from diseases requiring PC
 - 94% adults (69% >60 years old)
 - 6% children



(Global Atlas of PC at the End-of-Life - Connor and Sepulveda Bermedo 2014)

Therefore....

- 377 adults per 100,000 >15 years
- 63 children per 100,000 <15 years need PC at the endof-life



(Global Atlas of PC at the End-of-Life - Connor and Sepulveda Bermedo 2014)

What we know....

2011

Worldwide WPCA Palliative Care Development All levels (n = 234)



Level of Palliative care Development (PCD) Level 1. No known activity Level 2. Capacity building Level 3a. Isolated provision Level 3b Generalized provision Level 4a Preliminary integration Level 4b Advanced integration

The boundaries and names shown and the designations used on this map do not implythe expression of any opinion whatsoever on the part of the WPCA or WHO concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.



(Mapping levels of PC development: a global update. WPCA 2011)

Children's PC: A Systematic Review



Children 2014



So what???

Limitations

- End-of-life vs need
- Does not show the actual situation
- May have good PC for adults but not children and this is not reflected

However.....

- Shows great need
- Shows us great gaps
- Therefore we need to work towards sustainability as we develop palliative care provision

Principles to 'Developing services and working towards sustainability'





Nurses and PC in Africa.....



Number of inhabitants per Doctor.....

470:1 470.3 470:1 3901 3901 4703 4701 4701 4701 4701 4701 4703 4701 4703 3901 3901 4701 4701 4701 4701 4701 4701 470.1 4701 4701 4701 4701 470:1 470:1 4701 4701 470:1 470:1 470:1 470:1 470:1 1046 1046 1046 1046 470:1 470:1 1901 3901 3901 3901 3901 3901 3901 3901 390.1 390.1 390.1 390.1 390.1 390.1 390:1 390:1 390:1 390:1 390:1 390:1 1901 3901 3901 3901 3901 3901 3901 390.1 390.1 390.1 390.1 390.1 5001 5001 3903 3901 3901 5001 5001 3901 390.1 5001 5001 500.1 1701 500.1 1.200:1 4.000:1 1.100:1 1.800:1 2,700:1 500:1 700:1 750 1 500:1 2.200:1 650-1 900:1 900:1 900:1 900:1 900:1 900:1 900:1 850-9001 9001 9001 9001 850:1 900:1 900:1 900:1 900: 8501 800.1 900.1 900.1 900.1 8501 8001 9001 9001 9001 850:1 800:1 800:1 900:1 900:1 900:1 900:1 900:1 900:1 900:1 900:1 900:1 1:009 1:000 1:000 330-1 330-1 900-1 900:1 330:1 270:1 330:1 2701 900:1 330-1 330.1 3301 330-1

330.1



Not everybody in this word can see a doctor when in next. This is even

more sci in anex's where people suffer from tenine, war and diseases. Doctors of

(Doctors of the World, September 2007)



Public health model for palliative care



(Stjernsward et al 2007, Harding et al 2013)

Policy
Palliative care part of national health plan,
policies, related regulations

So how do we increase global access to palliative care whilst working towards sustainability?

(Achievements -Examples)



Advocacy – How many children need PC??



- UNICEF and ICPCN Study
- Need numbers for advocacy purposes
- No accurate figures





The study....





Initial results of the global study...

- Total Need: 21.644 Million
- **Specialist Need:** 8.163 Million
- 44.42 per 10,000 children
- Range 21 >100 per 10,000 children
- Therefore providing evidence that we need sustainable models of PC service provision in order to meet the need



Uganda - Policy

- A lot has happened in Uganda
- Now getting a policy
- Once the policy is in place, other issues that enhance sustainability will be put in place e.g.:
 - PC positions
 - Budget and workplan
 - National indicators
 - Standards etc.



Access to medications including opioids

- Patchy poor in many countries especially developing countries (Global State of Pain Treatment Access to medicines and palliative care. HRW 2011)
- Much advocacy being done



Collaboration....



- Essential
- Key component of sustainability
- Range of national, regional and international organisations:
 - IAHPC, WHPCA, WHO TAG, APCA, EAPC, APHC etc etc.



Access to medication

- "We now have access to oral morphine our patients are no longer in pain – the wards are quiet" (Nurse)
- "Oral morphine is now being provided through the MoH system – before, when we had to rely on donations, supply was sporadic, now we can receive it regularly and the system is sustainable as it is utilising normal government systems." (Doctor)





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Education


Increasing access.....

Welcome to ICPCN's e-learning programme.

Username julia

Password

Login

Create new account Lost password?

Home Courses

Remember username The ICPCN has recognised the need to make training on children's palliative care accessible and affordable to all who need training. Thus we have developed several short courses as part of a longer term strategy of providing elearning programmes on children's palliative care.

In order to take a course just click on the course title and you will be asked to register your details.



Courses	
▼Courses in English	
💱 Introduction to palliative care in children	[+-
Pain assessment and management for children: A training module linked to the WHO guidelines for persisting pain	[d=
Communicating with children and emotional issues	[+
Child development and play in children's palliative care	[d=
End-of-life care in children's palliative care	[4 -
Grief and bereavement in children's palliative care	ŀ
✓Formations en français	
💱 Introduction aux soins palliatifs de l'enfant	[+-
💱 Evaluation et gestion de la douleur chez les enfants: un module la formation liée au nouveau directives de l'OMS pour la douleur persistante.	_ [4-
Communiquer avec l'enfant et gestion des problèmes émotionnels	ŀ
«Курсы в России	
💱 Введение в паллиативную помощь детям	[+-
💱 Оценка и ведение болевого синдрома у детей. Краткий курс, включающий рекомендации ВОЗ по персистирующей боли. Последнее обновление	[d=
Коммуникации с детьми и решение эмоциональных проблем	ŀ
✓Kursevi na srpskom jeziku	
💱 Uvod u palijativno zbrinjavanje dece	[+
Procena i kontrola bola kod dece: kratak kurs koji se zasniva na novim smernicama SZO za kontrolu perzistentnog bola kod dece.	
▼Cursos de Español	
Introducción a los cuidados paliativos pediátricos	[+
💱 Valoración y tratamiento del dolor en niños:	[4 -
Comunicación con menores y problemas emocionales en cuidados paliativos pediátricos	(+)

▼Cursos em português	
Introdução aos cuidados paliativos de crianças	() (
💱 Avaliação e controlo da dor para crianças: Um pequeno curso associado às novas diretrizes da OMS para a dor persistente. Revisto em abril de 2012	[+ ()
Comunicar com crianças e questões emocionais	2

In Serbia.....







Razvoj palijativnog zbrinjavanja u Srbiji Projekat finansira Evropska unija





Oxford Policy Management

Mentorship & Supervision

- Essential
- Adds towards sustainability as skills are embedded in practice
- Often not part of regular training and the value of mentorship and modelling is not always appreciated

- "Our leaders involved us, and the mentorship gave us inspiration" (CHUK)
- "the mentors showed us how to do it, it was through their experiences that we learnt" (Kibagabaga)

Models of PC Delivery

ПАЛИЈАТИВНО ЗБРИЊАВАЊЕ

Integrate Project

- Strengthening & integrating PC into national health systems
- Integrated into:
 - Systems
 - Policies
 - Practice
 - Communities







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Link-nurse programme



- To improve palliative care provision within Mulago hospital
- Being extended to other hospitals in Uganda and surrounding countries





Patient care

- What it is all about!
- Palliative care and pain control is a human right:
 - Whoever we are
 - Wherever we live
 - Whatever our race
 - However old we are
 - Regardless of our illness



Challenges to increasing access to PC and working towards sustainability (1)



- I. Socio-cultural
- 2. Governmental, legalistic and national context
- 3. Service provider
- 4. Service user level
 - Clarifying the definition of palliative care in accordance with the WHO definition is key (2002)

Challenges (2)



- Meeting the complex needs of those needing palliative care
- Limited resources:
 - Lack of health and social professionals
 - Lack of funds
 - Lack of specific training
 - Lack of recognition of our role as nurses, social workers etc.
 - Lack of recognition of palliative care

Challenges (3)

- High burden of disease
- Need for different models of care
- Child headed households
- Conflict situations
- Fear of providing PC for children
- Ensuring PC is within policy



So why do we need to work towards sustainability?





Can we increase global access to palliative care and work towards sustainability?





"We too must not just talk the talk, But, like her, we must walk the walk, And stay the course, and continue the task of changing the world."

(Robert Twycross speaking about Dame Cicely Saunders March 2006)



