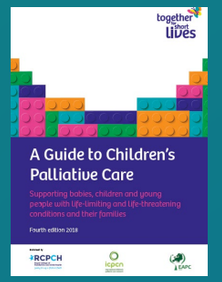
Advances and challenges in European Paediatric Palliative Care

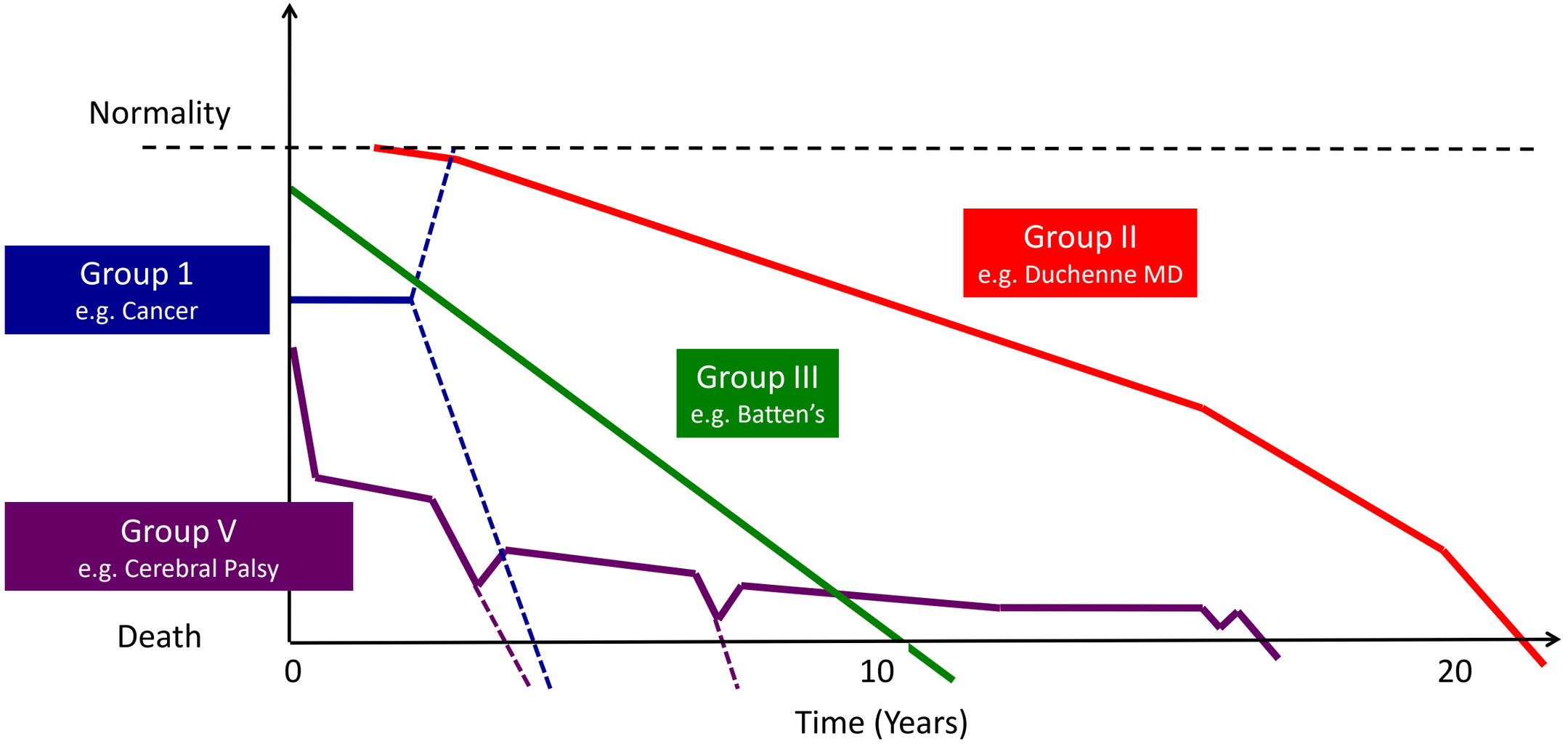
Julie Ling – CEO, European Association For Palliative Care

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support.



Together for Short Lives (2018) A guide to children's palliative care. 4th Edition
https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/

Disease trajectories in children



Over 21 million children and young people globally needing palliative care, yet only 5-10% of them having access to services, there remains much inequity within the field.

Connor SR, Downing J, Marston J. (2017) Estimating the global need for palliative care for children: A cross-sectional analysis. Journal of Pain and Symptom Management 53(2):171-177.
Connor SR (Editor) (2020) Global Atlas of Palliative Care. 2nd Edition. Worldwide Hospice & Palliative Care Alliance, London, UK.
Arias-Casais N, Garralda E, Rhee JY, et al. (2019) EAPC atlas of palliative care in Europe Vilvoorde: EAPC Press, 2019.

Around 7% of people who need palliative care globally are children. While the overall percentage might be small, the number of children and families around the world who are affected is large.

About 2.8% of the global total of children needing access to palliative care are in the European Region.

Original Article

PALLIATIVE MEDICINE

Palliative Medicine
1–11

DOI: 10.1177/0269216320975308
journals.sagepub.com/home/pmj


Estimating the current and future prevalence of life-limiting conditions in children in England

Lorna K Fraser[1], Deborah Gibson-Smith[1], Stuart Jarvis[1], Paul Norman[2] and Roger C Parslow[3]

Abstract

Background: Previous studies showed increasing number of children with a life-limiting or life-threatening condition who may benefit from input from pediatric palliative care services.

Aim: To estimate the current prevalence of children with a life-limiting condition and to model future prevalence of this population.

Design: Observational study using national inpatient hospital data. A population-based approach utilizing ethnic specific population projections was used to estimate future prevalence.

Setting/participants: All children aged 0–19 years with a life-limiting condition diagnostic code recorded in Hospital Episodes Statistics data in England from 2000/01 to 2017/18.

Results: Data on 4,543,386 hospital episodes for 359,634 individuals were included. The prevalence of children with a life-limiting condition rose from 26.7 per 10,000 (95%CI 26.5–27.0) in 2001/02 to 66.4 per 10,000 (95% CI: 66.0–66.8) in 2017/18. Using a more restricted definition of a life-limiting condition reduced the prevalence from 66.4 to 61.1 per 10,000 (95%CI 60.7–61.5) in 2017/18. Highest prevalence was in the under 1-year age group at 226.5 per 10,000 and children with a congenital abnormality had the highest prevalence (27.2 per 10,000 (95%CI: 26.9–27.5)).

The prevalence was highest among the most deprived group and in children of Pakistani origin.

Predicted future prevalence of life-limiting conditions ranged from 67.0 (95%CI 67.7–66.3) to 84.22 (95%CI 78.66–90.17) per 10,000 by 2030.

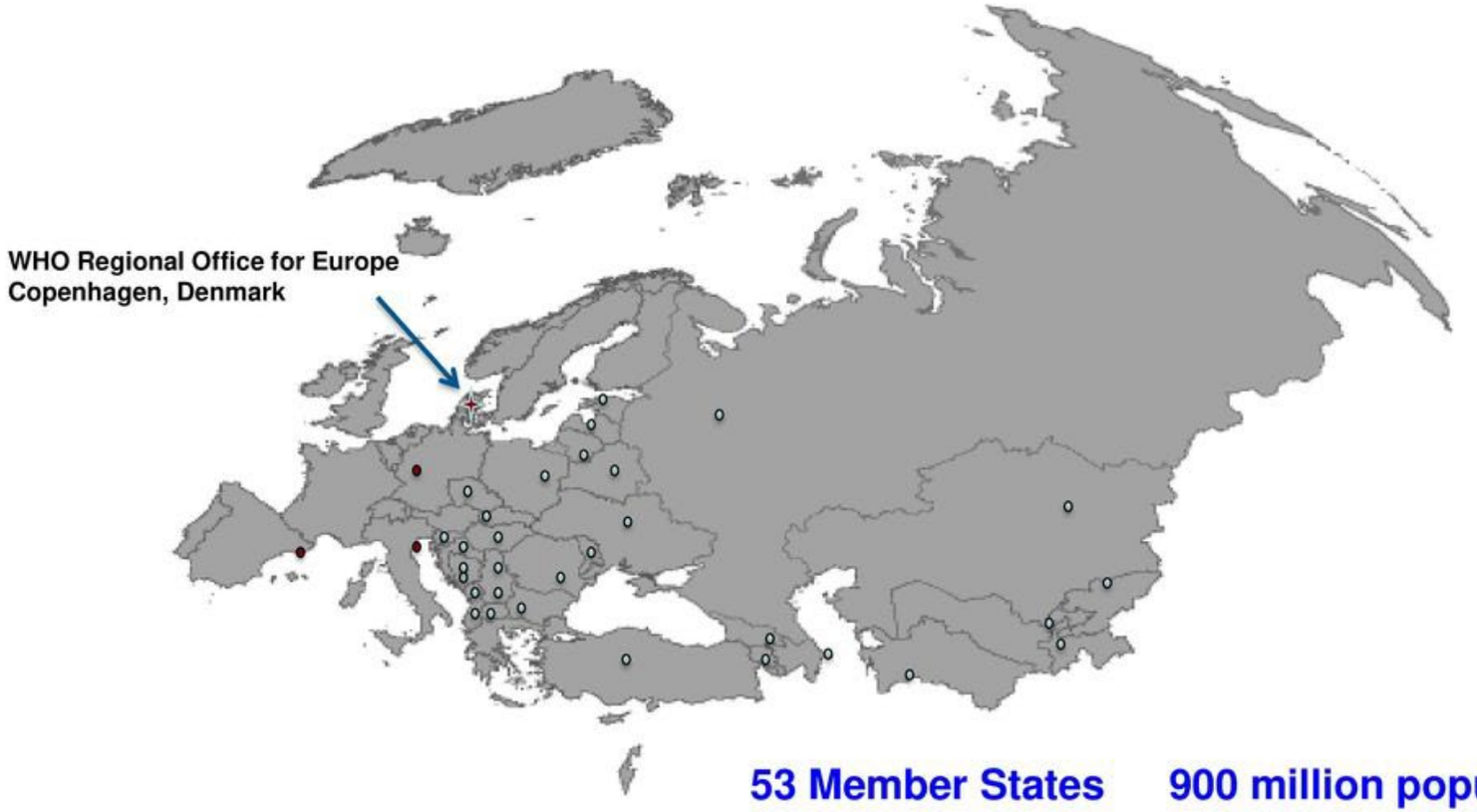
Conclusions: The prevalence of children with a life-limiting or life-threatening condition in England has risen over the last 17 years and is predicted to increase. Future data collections must include the data required to assess the complex health and social care needs of these children.

Changing populations:

1. In recent years, childhood deaths have decreased
2. Mortality in paediatric intensive care units has also declined but still 1:6 children die in PICU
3. No consensus on the number of children who have died who would benefit from palliative care
4. Children living longer and requiring increasing levels of care

Fraser L., Bluebond-Langner M, Ling J. (2020) Advances ad challenges in European Paediatric Palliative Care. Med. Sci ,8:20
Plunkett, A.; Parslow, R.C. Is it taking longer to die in paediatric intensive care in England and Wales? *Arch. Dis. Child.* **2016**, *101*, 798–802.

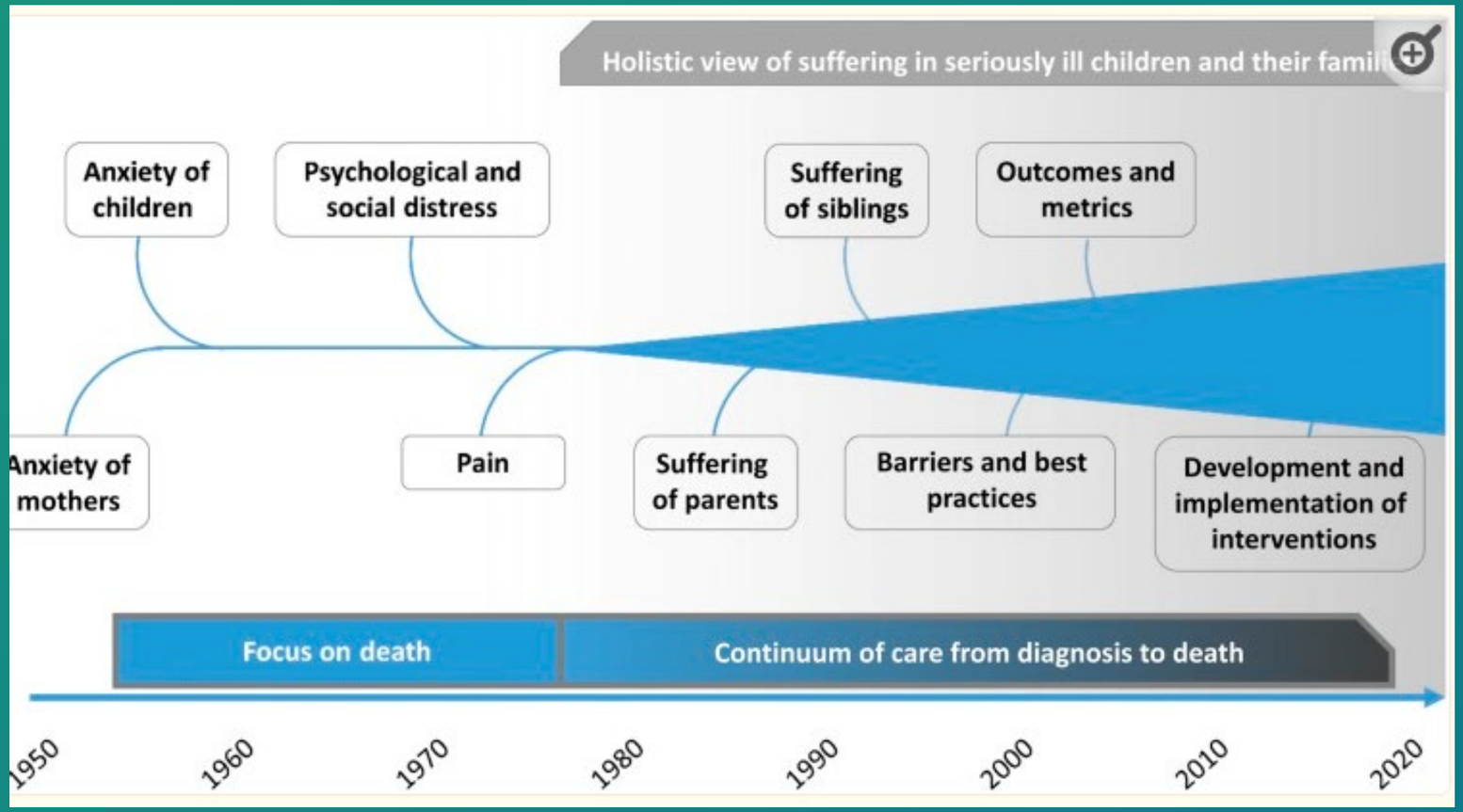
The WHO European Region



53 Member States **900 million population**

World Health Organization
REGIONAL OFFICE FOR Europe

How it all began….



Sisk al. (2020) Response to suffering of the seriously ill child: A History of Palliative Care for Children Pediatrics 145(1)e20191741


EAPC Atlas of Palliative Care
in Europe 2019
Natalia Arias-Casais, Eduardo Garralda, John Y. Rhee, Liliana de Lima, Juan José Pons,
David Clark, Jeroen Hasselaar, Julie Ling, Daniela Mosoiu, Carlos Centeno
PC

PPC CONSULTANTS AND PERINATAL PC REFERENCE CENTRES

COUNTRY	C	P
Albania	●	○
Armenia	●	○
Austria	○	●
Belarus	●	○
Belgium	●	○
Cyprus	●	○
Czech Republic	●	○
France	●	○
Georgia	●	○
Germany	●	●
Greece	●	○
Hungary	●	○
Ireland	●	○
Italy	●	●
Latvia	●	○
Netherlands	●	●
Norway	○	●
Russian Federation	●	○
Slovakia	●	○
Spain	●	●
Ukraine	●	○
United Kingdom	●	●

● **C:** Specialised PPC consultants
● **P:** Perinatal PC reference centre

20
Countries with specialised PPC consultants

7
Countries with perinatal PC reference centres

PPC COMPONENTS IN PAEDIATRICS TRAINING

COUNTRY	D	N
Albania	●	●
Armenia	●	●
Austria	●	●
Belarus	●	●
Czech Republic	●	○
Georgia	●	●
Germany	●	●
Hungary	○	●
Ireland	○	●
Italy	●	●
Latvia	●	●
Netherlands	○	●
Norway	○	●
Portugal	●	●
Serbia	●	●
Spain	●	●
Ukraine	●	○
United Kingdom	●	●

● **D:** for medical doctors
● **N:** for nurses

14
Countries with PPC components for doctors

16
Countries with PPC components for nurses

REPRESENTATIVE IN NATIONAL ASSOCIATION FOR PPC

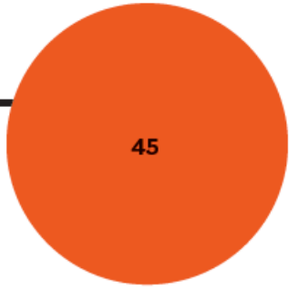
COUNTRY	P	PC
Austria	●	●
Belgium	○	●
Czech Republic	○	●
Denmark	●	○
Germany	○	●
Hungary	○	●
Ireland	○	●
Israel	○	●
Italy	○	●
Netherlands	●	●
Portugal	○	●
Russian Federation	○	●
Slovakia	●	○
Spain	●	●
Ukraine	●	○
United Kingdom	●	○

● **P:** PC representative in the national paediatrics association.
● **PC:** Paediatrics representative in the national PC.

7
PC representative in the national paediatrics association

12
Paediatrics representative in the national PC association

DAY CARE PROGRAMMES



Original Article

Mapping Pediatric Palliative Care Development in the WHO-European Region: Children Living in Low-to-Middle-Income Countries Are Less Likely to Access It

Natalia Arias-Casais, MD, MGH, PhD, Eduardo Garralda, MA, Juan José Pons, PhD, Joan Marston, RN, Lizzie Chambers, Julia Downing, PhD, Julie Ling, PhD, John Y. Rhee, MD, Liliana de Lima, MHA, and Carlos Centeno, PhD

ATLANTES Global Observatory of Palliative Care (N.A.-C., E.G., J.J.P., J.Y.R., L.d.L., C.C.), Institute for Culture and Society, University of Navarra, Pamplona; Department of History, History of Art and Geography (J.J.P.), University of Navarra, Pamplona, Spain; Department of Neurology (J.Y.R.), Massachusetts General Hospital and Brigham and Women's Hospital, Harvard, Boston, Massachusetts; Medical School (L.d.L.) International Association for Hospice and Palliative Care, Houston, Texas, USA; Palliative Treatment for Children (PatchSA) (J.M.), Rondebosch, South Africa; European Association for Palliative Care (J.L.), Vilvoorde, Belgium; Together for Short Lives (L.C.), Bristol; and International Children's Palliative Care Network (J.D.), Bristol, United Kingdom

Review

2008

Paediatric palliative care: challenges and emerging ideas

Stephen Liben, Danai Papadatou, Joanne Wolfe

Lancet 2008; 371: 852–64

Published Online
August 16, 2007
DOI:10.1016/S0140-6736(07)61203-3

See Editorial page 786

The Montreal Children's Hospital of the McGill University Health Center, Montreal, Quebec, Canada (S Liben MD); Faculty of Nursing, University of Athens, Greece (Prof D Papadatou PhD); Department of Pediatric Oncology and the Center for Outcomes and Policy Research of the Department of

Paediatric palliative care is an emerging subspecialty that focuses on achieving the best possible quality of life for children with life-threatening conditions and their families. To achieve this goal, the individuals working in this field need to: clearly define the population served; better understand the needs of children with life-threatening conditions and their families; develop an approach that will be appropriate across different communities; provide care that responds adequately to suffering; advance strategies that support caregivers and health-care providers; and promote needed change by cultivating educational programmes. Despite these challenges, advances in paediatric palliative care have been achieved in a short period of time; we expect far greater progress as the field becomes more formalised and research networks are established.

Introduction

Paediatric palliative care (PPC) is focused on ensuring the best possible quality of life for children whose illness makes it likely that they will not live to become adults. Such care includes the family and extends into the comprehensive approach to care. The child, family, and care providers have overlapping but differing concerns in terms of personal factors such as personality, values (including spiritual, religious, and cultural), cognitive ability, well-being, personal history, and experience;

Main challenges:

1. Defining palliative care
2. Better understanding the needs of paediatric palliative care
3. Integrating culture and spirituality into palliative care
4. Reducing suffering and promoting hope and healing
5. Acknowledging professionals’ responses and need or support
6. Integrating knowledge of paediatric palliative care into basic curricula and training programmes

medical sciences

2020

MDPI

Article

Advances and Challenges in European Paediatric Palliative Care

Lorna K Fraser [1], Myra Bluebond-Langner [2] and Julie Ling [3,*]

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2 Palliative Care for Children and Young People, Louis Dundas Centre, UCL Great Ormond Street Institute of Child Health, London WC1N 1EH, UK; bluebond@ucl.ac.uk
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Received: 11 February 2020; Accepted: 14 April 2020; Published: 17 April 2020

Abstract: Advances in both public health and medical interventions have resulted in a reduction in childhood mortality worldwide over the last few decades; however, children still have life-threatening conditions that require palliative care. Children's palliative care is a specialty that differs from palliative care for adults in many ways. This paper discusses some of the challenges, and some

Main challenges:

1. Dearth of evidence (decision making, communication and pain and symptom management)
2. Need for routine high-quality data
3. Best way to care
4. Place of care
5. Place of death
6. Advance care planning

TABLE 1 Remaining Challenges in PPC

Remaining Challenges in PPC
Insufficient training, funding, and infrastructure to support the development of PPC investi academicians
Insufficient research funding
Deficiency of metrics to demonstrate productivity and quality of PPC
Need for validated outcome measures for PPC interventions
Disparities in access to PPC, especially outside the hospital
Variable integration of specialist PPC teams
Global disparities in access to PPC
Gaps in seamless care from hospital to community at the end of life

PPC, pediatric palliative care.

Sisk al. (2020) Response to suffering of the seriously ill child: A History of Palliative Care for Children Pediatrics 145(1)e20191741

Ukraine war: Terminally ill children in Russia line up outside hospice in shape of 'Z' to show support for invasion

Vladimir Vavilov, chairman of a cancer charity that runs a hospice in the city of Kazan, organised their children and their mothers to line up to produce the letter.

Samuel Osborne
News reporter @samuelosborne93

Monday 7 March 2022 19:15, UK

Children and their parents formed the symbol outside the hospice. Pic: @kamilkazani

Terminally ill children flee war-torn Kharkiv on makeshift medical train

By Arwa Damon, AnneClaire Stapleton and Alex Platt, CNN
Updated 9:05 AM EST, Sat March 5, 2022

Video Ad Feedback

05:13 - Source: CNN

Inside the harrowing journey to evacuate critically ill children out of Ukraine

Mostyska, Ukraine (CNN) — The medical team is not entirely sure what to expect as the train creaks to a stop in the darkness near the Ukraine-Polish border, just inside Ukraine. A bus' headlights inch forward. Eugenia Szuszkiewicz can feel the anxiety balling up in her stomach.

The doctor's stress levels are through the roof. This is a dangerous journey for children who need palliative care in the best of circumstances. Now 12 of them are doing it in a war.

Small and frail bodies are hoisted up for the last time in weary mothers' arms as they descend from the

Special Article

International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS

Franca Benini, MD, Danai Papadatou, PhD, Mercedes Bernadá, MD, Finella Craig, MD, Lucia De Zen, MD, PhD, Julia Downing, PhD, Ross Drake, MD, Stefan Friedrichsdorf, MD, FAAP, Daniel Garros, MD, Luca Giacomelli, PhD, Ana Lacerda, MD, Pierina Lazzarin, BSc, Sara Marceglia, PhD, Joan Marston, RN, Mary Ann Muckaden, MD, Simonetta Papa, PhD, Elvira Parravicini, MD, Federico Pellegatta, RN, and Joanne Wolfe, MD

Paediatric Palliative Care, Pain Service, Department of Women's and Children's Health, University of Padua, Padua, Italy; Professor of Clinical Psychology, Department of Mental Health and Behavioral Studies, Faculty of Nursing, National and Kapodistrian University of Athens, Greece; Associated Professor of Pediatrics, School of Medicine, Universidad de la República, Pereira Rossell Hospital Center, Pediatric Palliative Care Team Director, Montevideo, Uruguay; Consultant in Paediatric Palliative Medicine at the Louis Dundas Centre, Great Ormond Street Hospital for Children, London, UK; Pediatric Palliative Care and Pain Service, Institute for Maternal and Child Health Burlo Garofolo, Trieste, Italy; International Children's Palliative Care Network (ICPCN), Uganda/UK; Pediatric Palliative Care and Pain Services, Starship Children's Health, Auckland District Health Board, Auckland, New Zealand; Professor in Pediatrics, Medical Director, Center of Pediatric Pain, Palliative and Integrative Medicine at UCSF Benioff Children's Hospitals in Oakland and San Francisco, California, USA; Department of Pediatrics, Division of Critical Care, University of Alberta, Edmonton, Alberta, Canada; Stollery Children's Hospital PICU, Edmonton,

opportunities for sharing of information, research, education and advocacy.

2. To support the development and dissemination of the evidence base in children's palliative care through identification of specific workstreams leading to published guidelines and standards.

3. To provide educational opportunities for those working in children's palliative care through the development of paediatric sessions at EAPC events.

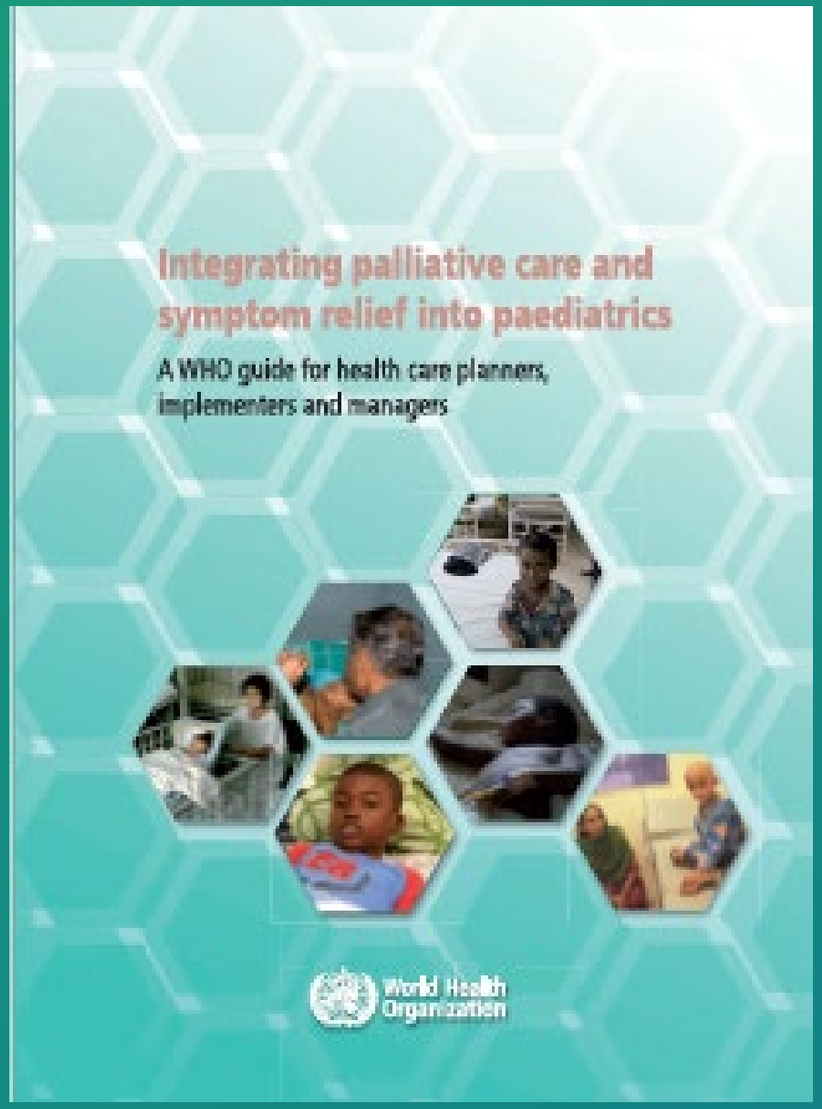
4. To support the development of palliative care for children and young people across Europe, through advocacy and awareness-raising, signposting organisations to the support offered by the International Children's Palliative Care Network, the guidelines and standards developed by the Paediatric Task Force and other useful resources.

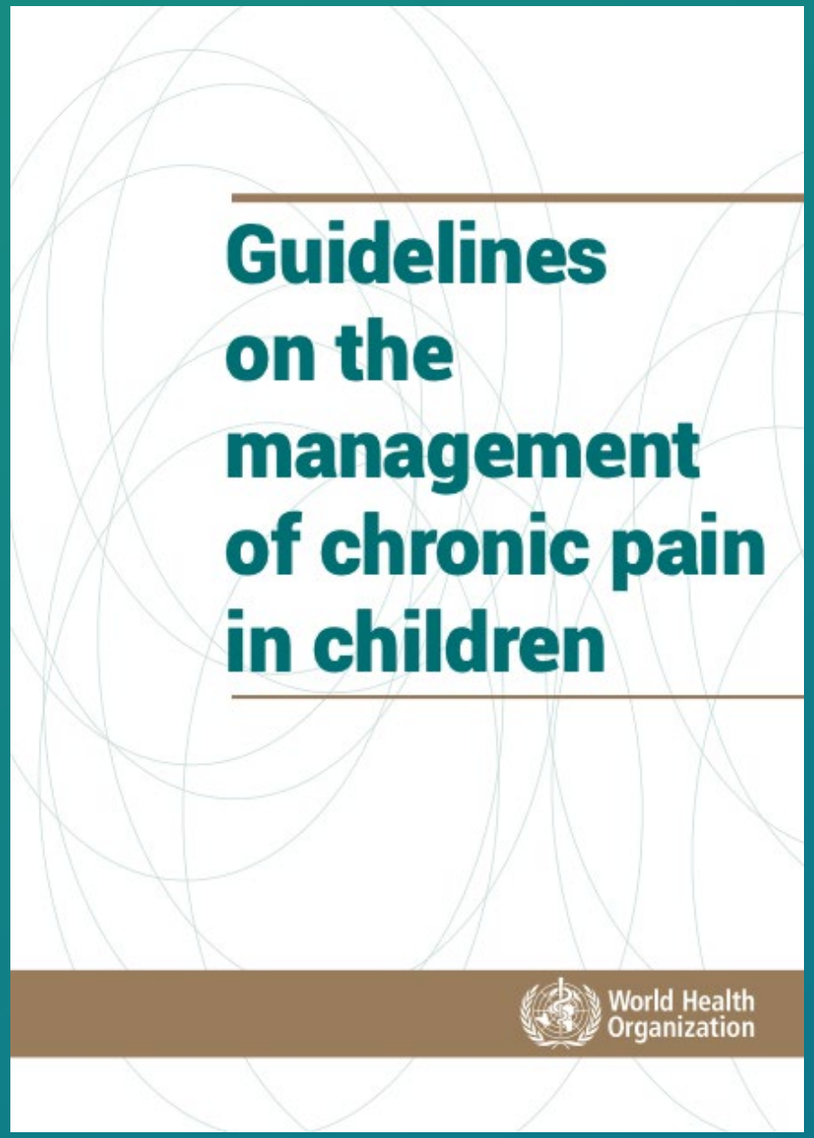
Meggie Schuiling-Otten

Co-Chair

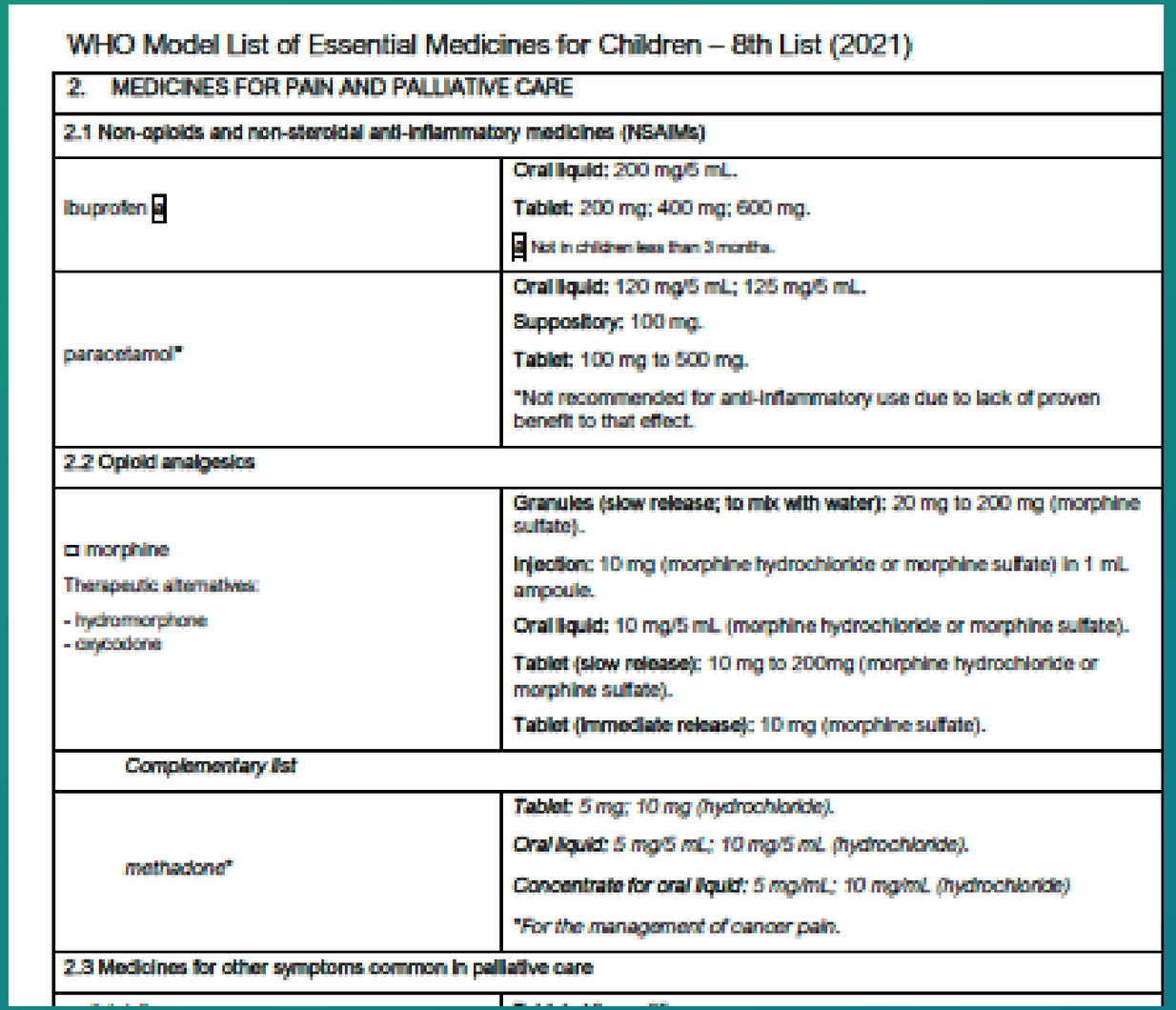
Ana Lacerda

Chair





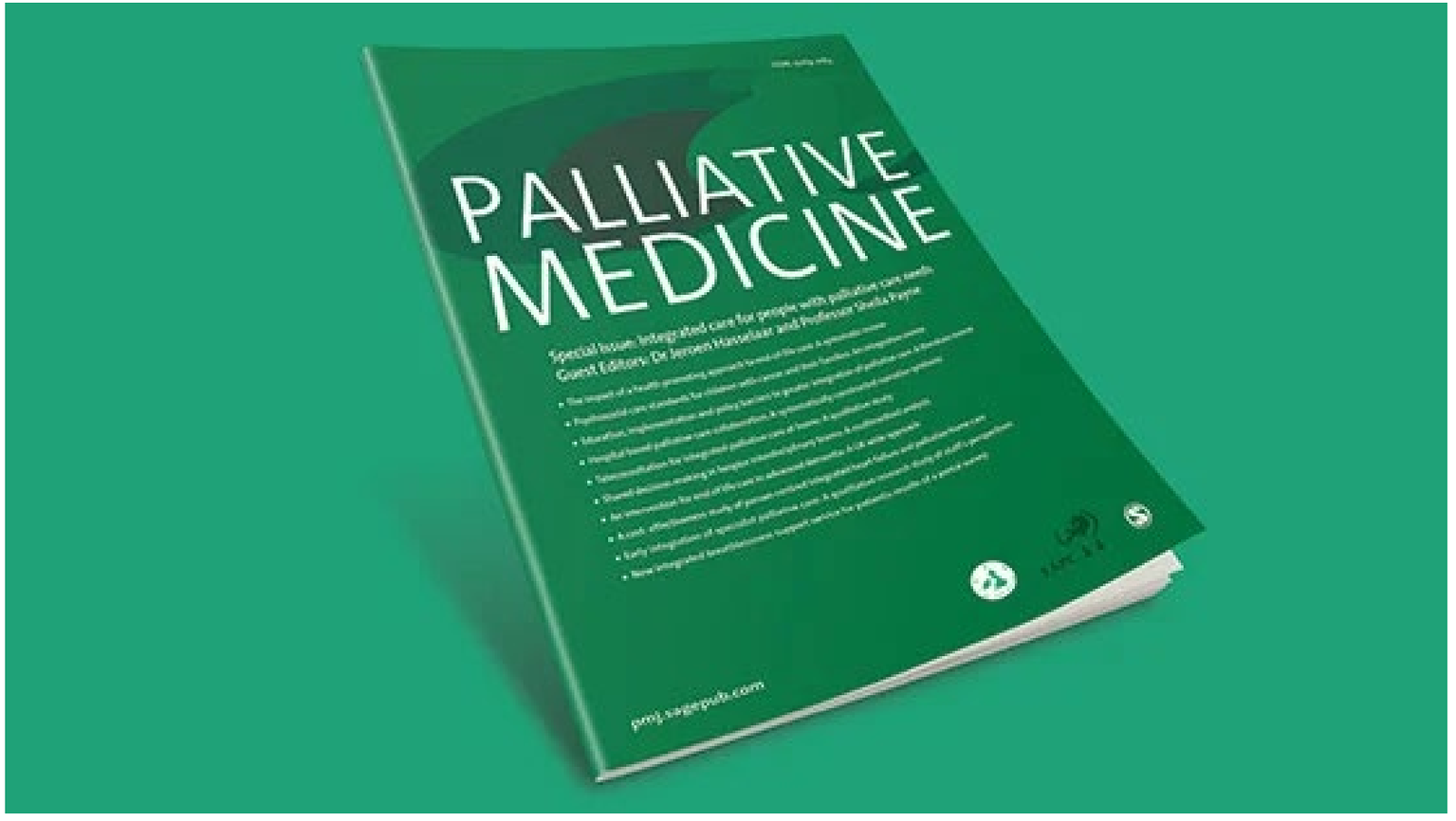
WHO (2018) Integrating palliative care and symptom relief into paediatrics. A guide for healthcare planners, implementers and managers www.who.int
WHO (2020) Guidelines on the management of chronic pain in children. www.who.int/palliativecare



WHO Model List of Essential Medicines for Children – 8th List (2021)

2. MEDICINES FOR PAIN AND PALLIATIVE CARE	
2.1 Non-opioids and non-steroidal anti-inflammatory medicines (NSAIMs)	
ibuprofen [a]	**Oral liquid:** 200 mg/5 mL. **Tablet:** 200 mg; 400 mg; 600 mg. [a] Not in children less than 3 months.
paracetamol*	**Oral liquid:** 120 mg/5 mL; 125 mg/5 mL. **Suppository:** 100 mg. **Tablet:** 100 mg to 500 mg. *Not recommended for anti-inflammatory use due to lack of proven benefit to that effect.
2.2 Opioid analgesics	
□ morphine Therapeutic alternatives: - hydromorphone - oxycodone	**Granules (slow release; to mix with water):** 20 mg to 200 mg (morphine sulfate). **Injection:** 10 mg (morphine hydrochloride or morphine sulfate) in 1 mL ampoule. **Oral liquid:** 10 mg/5 mL (morphine hydrochloride or morphine sulfate). **Tablet (slow release):** 10 mg to 200mg (morphine hydrochloride or morphine sulfate). **Tablet (immediate release):** 10 mg (morphine sulfate).
Complementary list	
*methadone**	***Tablet:** 5 mg; 10 mg (hydrochloride).* ***Oral liquid:** 5 mg/5 mL; 10 mg/5 mL (hydrochloride).* ***Concentrate for oral liquid:** 5 mg/mL; 10 mg/mL (hydrochloride)* **For the management of cancer pain.*
2.3 Medicines for other symptoms common in palliative care	

WHO (2021) Model List of Essential Medicines for Children (8th list). Geneva: World Health Organization http://www.who.int/medicines/publications/essentialmedicines/en/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SAGE

Paediatric palliative care research *has* come of age

When we were invited to edit a Special Issue of *Palliative Medicine* dedicated to paediatric palliative care research, we realized that bringing us together mirrors the spectrum of research in the field. Dr. Bluebond-Langner examines seriously ill children, their families, their healthcare providers and systems of care through an anthropological lens. Dr. Wolfe tests hypotheses from data collected in seriously ill children, their families, their healthcare providers and systems of care. In working together to develop this Special Issue, we hope to model the strength of blending qualitative and quantitative approaches to investigation, through which we can learn deeply about paediatric palliative care and generalize more broadly to disseminate our findings.

When we published the call for submissions, we asked the question, 'Has paediatric palliative care research come of age?' We got our answer, the response to the call was

palliative care is establishing goals through high-quality communication, a procedure grounded in specific skills. Re-goaling and further decision-making are also critical skills as serious illness evolves. In this issue, several studies further our understanding of these complex interventions. Janvier et al.[3] identify clinician communication behaviours that foster trust in parents of children with Trisomy 13 and 18. Cousino et al.[4] report from a study of adolescents and young adults listed for heart transplant that while they actively participated in the decision to pursue transplant, they also wanted further discussion about their end-of-life options and preferences. In a study of adolescents and young adults undergoing bone marrow transplant, Needle et al.[5] show that adolescents and young adults are capable of meaningful deliberation in making this and future treatment decisions. The results of these and other descriptive studies are important in the development of effective

Final thoughts….