



Children's Palliative Care: A Maternal and Child Health Issue

An ICPCN Briefing Paper

ICPCN
July 2012
Website: www.icpcn.org

The International Children's Palliative Care Network

The International Children's Palliative Care Network (ICPCN) was established in 2005 and is the only international organization bringing together individuals and organizations involved in the development and provision of palliative care for babies, children and young people. Present membership is from 81 countries. The vision of the ICPCN is a world where all life-limited children have access to palliative care services. The objectives of the ICPCN are Advocacy; Education and Research; Information- sharing and Networking. The ICPCN is a Registered Charity in England and Wales No: 1143712 and a Registered Company in England and Wales No: 767 172

The purpose of this paper is to highlight issues relating to maternal and child health and to consider how to develop links between maternal and child health initiatives and the palliative care of babies, children and young people in relation to potential international and national activity.

Maternal and Child Health

In 2010 a global initiative *Every Woman Every Child* was spearheaded by UN Secretary-General Ban Ki-moon, aiming to mobilise and intensify global action to improve the health of women and children around the world. *Every Woman Every Child* aims to work with governments, philanthropists, businesses and civil society groups around the world to save the lives of 16 million women and children and improve the lives of millions more. This initiative is promoting action behind the Global Strategy for Women's and Children's Health and the health-related Millennium Development Goals (MDGs).

The Global Strategy for Women's and Children's Health, sets out how individuals, organisations and nations can work together to improve the health of women and children and accelerate progress. It sets out the key areas where action is urgently required to enhance financing, strengthen policy and improve service delivery. These include:

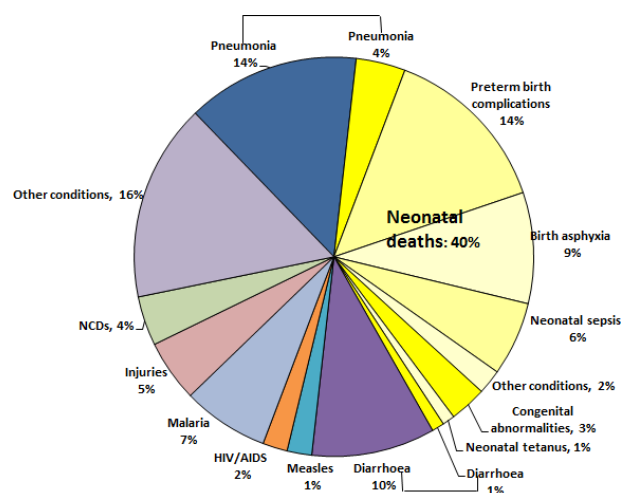
- Support for country-led health plans, supported by increased, predictable and sustainable investment.
- Integrated delivery of health services and life-saving interventions – so women and their children can access prevention, treatment and care when and where they need it.
- Stronger health systems, with sufficient skilled health workers at their core.
- Innovative approaches to financing, product development and the efficient delivery of health services.
- Improved monitoring

The Millennium Development Goals were adopted by 189 world leaders from rich and poor countries, as part of the Millennium Declaration which was signed in 2000. The health of women and children play a role in **all** MDGs, but especially within:

MDG 1: Eradicate extreme poverty and hunger: Poverty contributes to unintended pregnancies and pregnancy-related mortality and morbidity in adolescent girls and women, and under-nutrition and other nutrition-related factors contribute to 35% of deaths of children under

five each year (see table 1 and regional breakdown in Appendix 1), while also affecting women's health. Charging people less for health services reduces poverty and makes women and children more willing to seek care.

Table 1 Major Causes of Death in neonates and children under 5yrs old, Worldwide 2010



MDG 2: Achieve universal primary education: Gender parity in education is still to be achieved. It is essential because educated girls and women improve prospects for the whole family, helping to break the cycle of poverty. In Africa, for example, children whose mothers have been educated for at least five years are 40% more likely to live beyond the age of five.

MDG 3: Promote gender equality and empower women: Empowerment and gender equality improve the health of women and children by increasing reproductive choices, reducing child marriages and tackling discrimination and gender-based violence.

MDG 6: Combat HIV/AIDS, malaria and other diseases: Many women and children die needlessly from diseases that we have the tools to prevent and treat. In Africa, reductions in maternal and childhood mortality have been achieved by effectively treating HIV/AIDS, preventing mother-to-child transmission of HIV and preventing and treating malaria. Hain et al (2010)¹ have compiled a list of 574 ICD10 diagnoses that have been judged by professionals working in paediatric palliative care to be life-limiting and drawn from admissions to children's hospices and referrals to specialist paediatric palliative medicine.

In an ICPCN online survey to identify the most common diagnoses of children needing palliative care² conducted by Professor Julia Downing in 2011 with 248 respondents from 84 countries, the following diagnoses were identified as the most common seen in children cared for in palliative care services:

1. Malignancies
2. Non-malignant

¹ Hain et al (2010), Directory of life-limiting diagnoses in children, based on ICD10codes, Unpublished work on behalf of ACT

² ICPCN International Survey conducted by Professor Julia Downing in 2011

- Cardiac
- Neurological
- Metabolic/ Neurodegenerative
- Chromosomal/ Syndrome
- Respiratory
- Genetic blood diseases
- Other e.g. HIV, renal failure etc

MDG 7: Ensure environmental sustainability – safe drinking water and sanitation: Dirty water and inadequate sanitation cause diseases such as diarrhoea, typhoid, cholera and dysentery, especially among pregnant women and vulnerable babies and children, so sustainable access to safe drinking water and adequate sanitation is critical.

MDG8: Develop a global partnership for development: Global partnership and the sufficient and effective provision of aid and financing are essential. In addition, collaboration with pharmaceutical companies and the private sector must continue to provide access to affordable, essential drugs as well as to bring the benefits of new technologies and knowledge to those who need them most. Approximately 20 million children worldwide are believed to be in need of palliative care services.

Children's Palliative Care

The goal of palliative care is the relief of suffering and the improvement of quality of life. ICPCN believes that babies, children and young people with life-threatening, life-limiting and chronic diseases or conditions have the right to receive palliative care for the relief of their suffering and enhancement of quality of life. Countries would need to put the following in place

Many medications are unavailable in paediatric formulations and prescribers are often untrained in the use of pain medications, especially opioids, in children. Most adults have an inherent belief that children should not die and therefore ignore the needs of these children.

While we believe that the primary focus of health care must be cure and the promotion of health, in reality, health care services for children with chronic conditions are often inadequate to meet the multiple and complex needs of these children and their families. Another sad reality is that children in developing countries often present at health services too late for cure. Added to this, there are still many childhood diseases and conditions which are, by their nature, incurable.

Children suffer physical pain, distressing symptoms and emotional and spiritual pain, but are often unable to express this due to their age, lack of verbal skills or disability. Few health care professionals are trained and skilled at evaluating children's pain and suffering, and therefore this is left unrecognised, ignored and untreated. Acknowledgement and support for spiritual pain and conflict; and the impact of culture and language, is mostly ignored in children. Children and families also have specific communications requirements due to the very nature of surrogate

decision making. Children who live to young adulthood need transitional support for them to transfer from children's to adult palliative care, when this is their wish. Children dying in pain and suffering leave families and health care workers with complex emotions and feelings of guilt and inadequacy.

Children grieve differently than adults according to their particular developmental stage and these children are often left to grieve alone and unsupported, which then further erodes the remaining family structure.

Call to Action

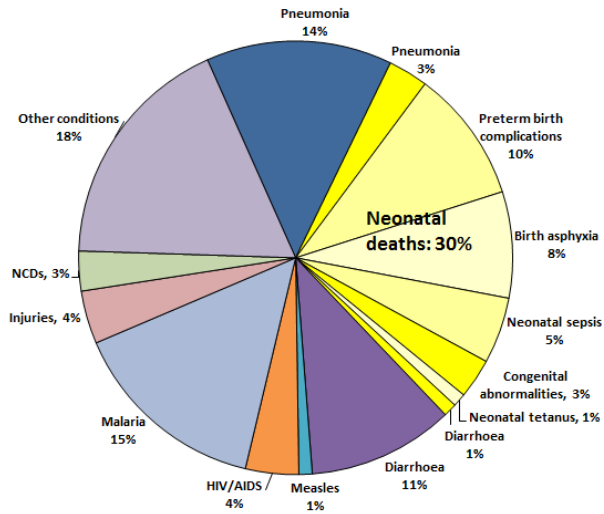
The International Children's Palliative Care Network (ICPCN) encourages members to consider how to raise awareness of children's palliative care within their own countries and use this awareness to encourage governments and international agencies address the need for countries to provide palliative care services for babies, children and young people as an essential element of the child's right to health, for children with chronic, life-threatening or life-limiting conditions. This includes neonates and children with disabilities. Action might include:

- Working together with other agencies and professionals to develop health plans which include plans for the development of palliative care for babies, children and young people.
- Ensuring that women and children have access to a universal package of guaranteed benefits, including family-planning information and services, antenatal, newborn and postnatal care, emergency obstetric and newborn care, skilled care during childbirth at appropriate facilities, safe abortion services (when abortion is not prohibited by law), and the prevention of HIV and other sexually transmitted infections.
- Access to appropriate ready-to-eat foods to prevent and treat malnutrition.
- Planning and delivering integrated care and access to health promotion to help prevent and treat diseases such as diarrhoea, HIV/AIDS, malaria, tuberculosis, and non-communicable diseases.
- Stronger links must be built between disease-specific programs (such as for HIV/AIDS, malaria and tuberculosis) and services targeting women and children (such as the Expanded Programme on Immunization, sexual and reproductive health and the Integrated Management of Childhood Illness).
- Strengthening health care systems to deliver integrated, high-quality services. They should extend the reach of existing services, especially at the community level and to the underserved, and manage scarce resources more effectively.
Building equitable approaches to health to ensure that vulnerable babies, children and young people can access medical expertise and drugs, the essential medicines for children, including opioids and other pain-relieving medications, be available and in paediatric formulations
- Building workforce capacity to deliver integrated care by developing strategies to train, retain and deploy health workers e.g. palliative care for children, including pain management, should be included in the undergraduate and postgraduate trainings of all health care professionals

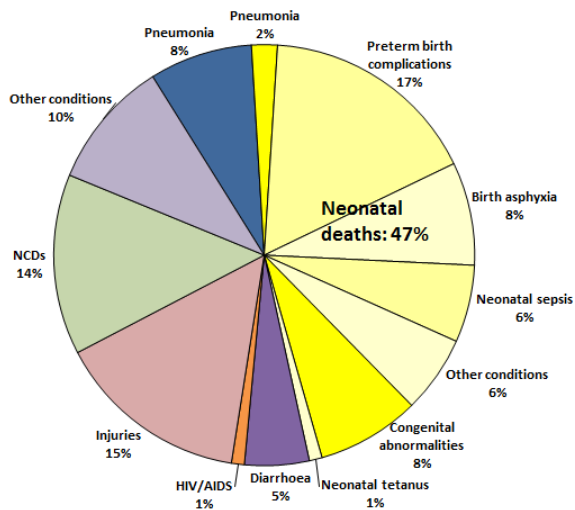
- Developing coordinated research and innovation to increase efficiency and provide high quality care.

Appendix 1 Major causes of death in neonates and children under 5yrs old in 2010

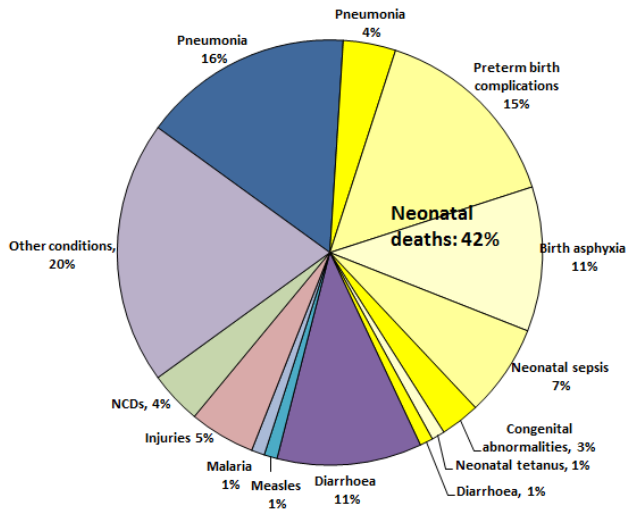
African Region



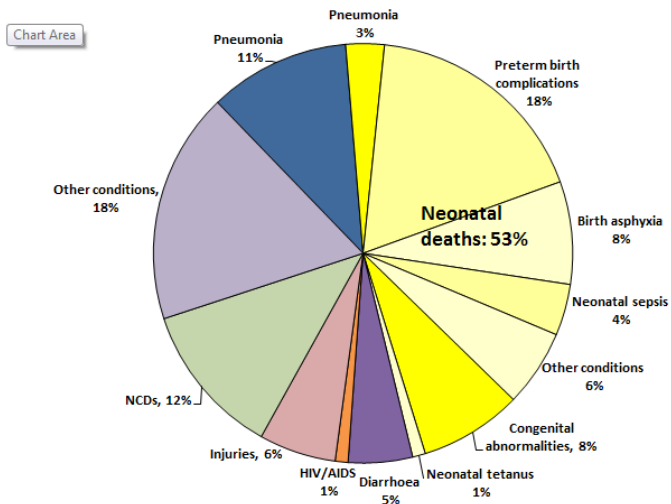
Region of the Americas



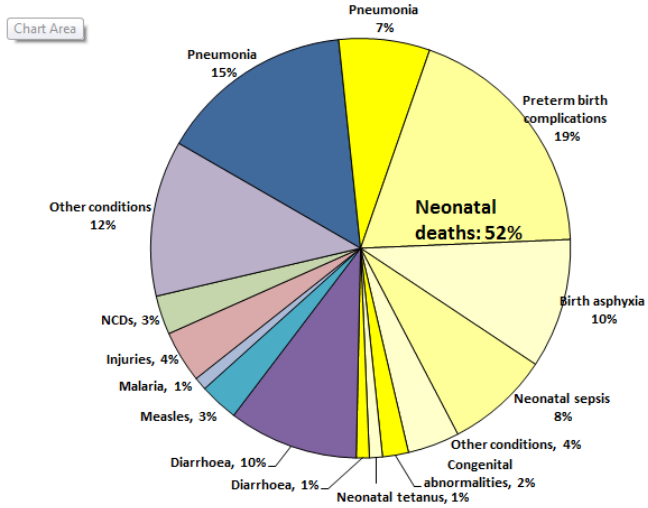
Eastern Mediterranean Region



European Region



South East Asia Region



Western Pacific Region

