International Children’s Palliative Care Network: A Global Action Network for Children With Life-Limiting Conditions

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Abstract

The International Children’s Palliative Care Network (ICPCN) is a global network of individuals and organizations working together to reach the estimated 21 million children with life-limiting conditions and life-threatening illnesses. The drive to establish the ICPCN was born from the recognition of the gaps in service provision for children’s palliative care and the need to collaborate, network, and share resources. Established in 2005 during a meeting in Seoul, South Korea, the ICPCN has developed over the years into an established network with a global membership. The history of the organization is described, including some of the key events since its inception. Working in collaboration with others, ICPCN has five key focus areas: Communication; Advocacy; Research; Education; and Strategic development, and is the only international charity working globally for the rights of children with palliative care needs. Activities in these areas are discussed, along with the inter-connection between the five areas. Without the ICPCN, palliative care for children would not have developed as far as it has over the years and the organization is committed to ongoing work in this area until all children requiring palliative care have access to quality services, wherever they live around the world.

Key Words

Pediatric, children, palliative care, global, network, international

“We ask that the voice of these children and young people be heard, respected and acknowledged as part of the development of palliative care worldwide”

From the Founding Statement of Korea of the International Children’s Palliative Care Network (ICPCN)

The ICPCN

The ICPCN is a global network of individuals and organizations working together to reach the estimated 21 million children with life-limiting conditions and life-threatening illnesses, whose quality of life would be improved by access to palliative care provided by health care workers with specific education and skills in the provision of children’s palliative care (CPC). The vision of ICPCN is “to live in a world where CPC is acknowledged and respected as a unique service, and every child and young person with life-limiting or life-threatening conditions and their families can receive the best quality of life and care regardless of which country they live in. ICPCN shares a vision that the total need of life-threatened or life-limited children should be met to encompass physical, emotion, spiritual and developmental aspects of care”.

Thus, the mission of ICPCN is “to achieve the best quality of life and care for children and young people with life-limiting conditions, their families and carers worldwide, by raising awareness of CPC, lobbying for the global development of CPC services, and sharing expertise, skills and knowledge”.

Working in collaboration with others, ICPCN has five key focus areas: Communication; Advocacy; Research; Education; and Strategic development, and is the only international charity working globally for the rights of all children with palliative care needs.

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Background: the Need for CPC and the ICPCN

The impetus to establish the ICPCN was born from a desire to raise awareness of the unique and specific palliative care needs of babies, children, and young people, and for these to be seen as distinct from adult palliative care. The founders wanted to develop a network that could share good practice and expertise and enable agencies across the world to develop a range of dedicated CPC services both within government systems and in community services. CPC is defined by the World Health Organization (WHO) as representing “a special, albeit closely related field to adult palliative care and is defined as follows:

- Palliative care for children is the active total care of the child’s body, mind, and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers, and even in children’s homes”.

The need for palliative care for children is great, with recent studies estimating that more than 21 million children around the world need palliative care at any one time, with approximately eight million of these needing specialist palliative care. Yet, when looking at service provision around the world, there are many gaps. A systematic review of CPC programs in 2011 found that globally 65.6% of countries had no known CPC activities and only 5.7% had provision that was reaching mainstream providers. More recent studies have identified this gap, for example, it was estimated that 801,155 children in South Africa need palliative care yet there was limited CPC service coverage in the public sector, with existing services being localized, with minimal reach. It was also estimated that in 2014, <5% of the children needing palliative care in South Africa are receiving it, and for those that are, care is mainly focused at the end-of-life. Availability of services differs from country to country, with countries where there is a high HIV burden and/or low resource settings having a higher need for CPC, with less accessibility of services. Barriers to the development of CPC have been identified, including lack of referrals, often because of a lack of knowledge about palliative care and negative attitudes from some health workers; challenges to when children start needing palliative care, for example, at what course of their illness, and the lack of clear inclusion criteria; lack of awareness and understanding by the community with regards to CPC; a lack of education for health professionals; human resources; access and availability of medications such as oral morphine; and financing of CPC services. Figure 1 shows the current status of CPC around the world completed through an ongoing mapping exercise of service provision.

Before the establishment of the ICPCN, many children’s hospice and palliative care services worked in isolation, and had little regular communication with each other. Although at that time most existing services were in high-income countries, and the greatest development was in the U.K., there were some excellent, innovative, and effective programs in low- and middle-income countries. Recognizing that we could learn from each other, share best practice, and become a stronger advocacy voice both within the

Fig. 1. Current status of children’s palliative care globally.
existing palliative care community and in general health services, a decision was taken to ensure regular communication and networking through the development of an international network.

**The History of the ICPCN**

In 2003, it was recognized that all CPC professionals face common experiences and that there are many opportunities for sharing information and providing support, as well as opportunities for mutual learning and collaboration. At a seminar in The Hague, arranged by Help the Hospices U.K., a decision was therefore taken to form a virtual global network for CPC. However, the active establishment of the ICPCN as a global collaborative only took place after a meeting of representatives from 15 countries in Seoul, South Korea, in 2005. Founding members of the inaugural co-ordinating committee included representatives from the U.K., South Africa, Costa Rica, Poland, Romania, Canada, and the U.S., with secretarial support provided by Help the Hospices and the Hospice Information Service in the U.K.

Later, in 2006, a Steering Committee was formed with representation from different regions of the world and a decision was taken to keep the ICPCN under the auspices of Association for Children’s Palliative Care (ACT) (Now Together for Short Lives) as a collaborative partnership, but to have the headquarters in South Africa, being a country with elements of both the developed and the developing world. The Hospice Palliative Care Association of South Africa agreed to hold and manage any funding and to support the development of the ICPCN. This they continued to do until 2011. Joan Marston from South Africa was appointed as the Chair with Barbara Gelb (Children’s Hospices U.K.) and Lizzie Chambers (ACT) as Co-Vice-Chairs. Initially, the work of the ICPCN was carried out by active volunteers from the steering committee, with the Chair and Vice-Chairs acting as the executive and management. From the first strategic planning session in 2006, certain strategic activities were identified as crucial to the development of CPC globally and these included that of communication, particularly with regards to the development of a Web site, advocacy, education and research, and sustainability of CPC services and ICPCN itself.

At the end of 2007, ICPCN’s first Web site was launched and an International Information Officer was employed (funded through The True Colours Trust, U.K.). Thus, Sue Boucher started working of ICPCN. With a background in education and publishing and an established author of numerous teaching text books and children’s story books, she brought expertise to the organization that was sorely needed. This appointment was key to the development of the ICPCN and led to a rapid growth in membership and formal communication through regular newsletters and an active and up-to-date Web site: www.icpcn.org. Mapping of services began at this time; and through regular informal mapping exercises, the ICPCN has been able to show the development of CPC in different countries and regions of the world (Fig. 1).

It was at this time that the ICPCN really became the global “One Stop Shop” or hub of information for CPC. October 2007 saw the publication of the ICPCN Charter of rights for life-limited and life-threatened children. This charter sets the international standard of support that is the right of all children living with life-limiting or life-threatening conditions and their families. It has since been translated into 25 languages and can be downloaded from the ICPCN Web site.

In 2009, a partnership with Children’s Hospice International brought the 1st international congress on CPC to Africa. The congress, held in Cape Town, South Africa, inspired The ICPCN Declaration of Cape Town, which calls on the palliative care community to collaborate and share resources and knowledge to advance CPC globally. Under ICPCN leadership, The Beacon Project to develop CPC in South Africa, Tanzania, and Uganda was launched with funding from The Diana Princess of Wales Memorial Fund and led to the development of the first Diploma in Africa in Paediatric Palliative Care, now available through Mildmay Uganda.

2010 saw the ICPCN partnering with Dr. Richard Hain and Cardiff University for the 5th International Cardiff Paediatric Palliative Care Congress in Wales. This partnership was repeated in 2012 and 2015 and is ongoing. In October 2010, the U.K. Department of International Development approved a proposal submitted by Help the Hospices to work with ICPCN to improve access to palliative care for children with HIV and other life-limiting conditions in Malawi and the Maharashtra District of India, over a five-year period. This advocacy project successfully developed new programs in both countries and led to the inclusion of CPC in national associations and government policies in Malawi and Maharashtra.

2011 was another “watershed” year for the ICPCN when it became an independent charity, registered in England and Wales, with a Board of Trustees. Joan Marston was appointed as the first Chief Executive and Prof. Julia Downing as a part-time Consultant to lead on Education and Research. A key ICPCN publication came out in October 2011 to coincide with World Hospice and Palliative Care Day. This publication, “Touching Rainbows, Acknowledging the Child’s Voice in Palliative Care,” gave a voice to children and
their families from across the world whose lives had been touched by the provision of CPC. Sister Frances Dominica, founder of the world’s first children’s hospice in the U.K., was invited to become ICPCN’s first Patron in 2011 and Dr. Kathleen Foley joined her as a Patron in 2016.

In partnership with the Kenya Hospice and Palliative Care Association, ICPCN provided the first ever in-country training in CPC to 42 pediatricians, doctors, and nurses, leading to the opening of the first CPC unit in Garissa, Kenya. ICPCN was invited onto the expert advisory group that developed the WHO Guidelines for the Management of Persisting Pain in Children with Medical Illnesses. This led to the beginning of the ICPCN e-learning program on pain management in children linking to the newly published WHO guidelines on persisting pain in children with the e-learning being recommended within the guidelines document. ICPCN was also appointed to coordinate research linked to these guidelines.

In 2012, thanks to generous funding from the True Colours Trust, the Monument Trust, and the Open Society Foundations International Palliative Care Initiative, further staff could be appointed to support the growing need for CPC development, education, advocacy, and communication. Busi Nkosi was appointed as the Advocacy Manager and Barbara Steel as the Administrative and Finance Manager. Training in CPC was provided to health professionals in several countries including Brazil, Kenya, and Swaziland.

eHospice, a Web site and app that reports global news and intelligence on hospice and palliative care, was launched in 2012. ICPCN took on the role of editing the International Children’s edition and stories are shared from many countries around the world. This is linked to social media platforms to enhance the reach of these stories.

As part of a global palliative care initiative in 2013, ICPCN advocated to the World Health Assembly (WHA) for the development of CPC services, the provision of appropriate pain medications in formulas for children and the training of relevant service providers. This led to the historic WHA Resolution on Palliative Care 67.19 of 2014 that included special references to children. Education remained a cornerstone of ICPCN’s work and the training of relevant service providers. This is linked to social media platforms to enhance the reach of these stories.

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The official launch of the “NOW Campaign” for children with life-limiting conditions took place in 2015, in celebration of ICPCN’s 10 years of successful advocacy and support for the development of CPC training and services worldwide. The launch was held at the Asia Pacific Hospice Conference in Taipei along with the premiers of the Little Stars documentary, filmed by the Australian film production company Moonshine Movies with narration by the well-known actor, David Suchet. Pope Francis gave his blessing on the ICPCN NOW campaign sending the members of the network his best wishes for the occasion while encouraging our continued efforts on behalf of the children in need of palliative care.

A successful side event on CPC, the first of its kind, was held at the 68th WHA in Geneva, Switzerland, which was unexpectedly attended by Dr. Margaret Chan, Director General of WHO. Referring to the palliative care resolution passed at the 67th WHA she said, “We are very pleased to be able to work with you to get this resolution going. Now the important thing is to implement it. To support countries to continue to do their best for the group of children with special needs.”

ICPCN’s 2nd International Conference on CPC was held in Buenos Aires in May 2016. The theme of the
conference was “Children’s Palliative Care. Now” and emphasized the need for palliative care for children now, as in the future it may be too late. Participants attended from 40 countries and the conference highlighted the ongoing issues in CPC and how we can learn from each other. The Commitment of Buenos Aires called on governments to implement the WHA resolution and ensure access to palliative care for children and young people. A new campaign “Just one thing” (JOT) was also launched at the conference. JOT aims to get 21 million commitments from individuals around the world to do “one thing” to help reach the 21 million children who need palliative care. The end of 2016 also saw Prof Julia Downing becoming the Chief Executive of ICPCN on the retirement of Joan Marston.

Communication

As a network with members from around the world, communication is key to all that the ICPCN does. The Web site (www.icpcn.org), is a hub of information on CPC. Updated on a regular basis, it provides information on what is happening in CPC around the world, the work of the ICPCN, information on training events, including the ICPCN’s e-learning programs and other postgraduate programs around the world. A listing of events of interest to CPC is provided and CPC conferences are specifically highlighted. Some of the important information on the Web site is information about CPC itself for instance the definition, which children need care, models of care etc. along with some of the resources available such as the textbook on CPC in Africa, the Really Practical Handbook of CPC, the different charters and commitments on CPC, ICPCN position papers, links to resources on other Web sites such as the Together for Short Lives Web site, the WHO guidelines to the management of persisting pain in children and many other resources available both in English and other languages.

The International Children’s edition of ehospice provides opportunities to share news items, trainings, events, and advocate for CPC. Edited by ICPCN, stories are written from people around the world and submitted for publication. It is a great way of getting information published and finding out what is happening around the world in terms of CPC. It also links in to the other editions of ehospice, thus expanding the reach to palliative care in general, enabling practitioners to put CPC in the context of general palliative care provision and development around the world.

Social media plays an important part in any organization’s communications, with ICPCN being active on different sites such as Facebook, Instagram, and Twitter. Regular information is disseminated through social media, and regular tweet chats are held on important issues with individuals from around the world. These play an important role in disseminating information about CPC, and offer a forum where others can ask questions and get involved in global discussions.

Communication also forms the backbone of many other ICPCN activities, such as advocacy, as we are advocating for the development of CPC, and trying to raise awareness, we are doing this through our campaigns, such as “Hats on” for CPC and the “JOT” campaign—both of these feature highly in the work of the communications department, drawing together work from the different departments to strengthen the campaigns. For example, the ICPCN Commitment of Buenos Aires published in May 2016 acknowledges the numbers of children who need palliative care, and states that “all children with life-threatening and life-limiting conditions have the right to receive quality palliative care provided by trained professionals and support workers, wherever they live in the world.” It goes on to note the unacceptable unmet need of children requiring palliative care and ends with a call to action. Thus, individuals are asked to do “JOT” in response to this call for action and to ensure that every child in every corner of the globe received the necessary palliative care that is their right. This brings together not only the communications side of ICPCN, but also the research work of the ICPCN—how many children need palliative care?, the advocacy work of the ICPCN—the Buenos Aires commitment and calling on individuals and governments to act—the education aspect of ICPCN as many people are committing to provide education to others.

Advocacy

ICPCN represents the voice of the children needing palliative care around the world, and advocating for the availability of CPC globally is a core activity of the organization. However, it cannot do this alone, and so works in collaboration with many other organizations, for example, the Worldwide Hospice and Palliative Care Alliance, the International Association of Hospice and Palliative Care, the Elizabeth Kübler-Ross Foundation, the European Association of Palliative Care, the African Palliative Care Association, the Asia Pacific Hospice and Palliative Care Network, the Latin American Hospice Palliative Care Association, and the UN Social Protection, Care and Support Working Group, to name but a few. ICPCN also has some Ambassadors and Champions who are working on their behalf to raise the profile of CPC—these include Global Ambassadors such as Micheline Etkin, Roberto Manrique, and Svetlana Statkevich, a Youth Ambassador Lucy Watts, and Global Champions,
Richard Newton, Cateline Khoo, Marquardt Petersen, and Brian Chamouleyron.

ICPCN also works closely with the WHO, and is a member of the WHO ad hoc Technical Assistance Group responding to the WHA resolution. ICPCN promoted and ensured the inclusion of children in the wording of this resolution, which seeks to develop, strengthen, and implement palliative care policies. Essential in this resolution is the global provision of appropriate pain medications, including children’s formulas, and the training of relevant service providers.

Advocacy is provided not just at the international level, but also ICPCN often has a role at the national level, working hand-in-hand with individuals or organizations in country. ICPCN has held meetings with senior health department officials to encourage the development and integration of CPC in-country. Countries where ICPCN have been involved include Argentina, Brazil, India, Lesotho, Malawi, Kenya, Norway, Serbia, Czech Republic, South Africa, Swaziland, Namibia, and Zambia, to name but a few.

Research

There is an urgent need to develop an evidence base for CPC globally. As the demand for CPC grows, there is a need for evidence by which to strengthen service delivery. This lack of evidence was noted during the process of developing the WHO guidelines on persisting pain for children, with the WHO calling for “a collaborative effort to cover the identified priority research areas and related systematic reviews of evidence.” Although this focuses specifically on the lack of research in the area of pain management in children, this dearth of evidence is also found elsewhere, for example, in a review of CPC in sub-Saharan Africa, only five peer-reviewed papers were found on CPC, and a lack of research was seen as a barrier to the ongoing development of CPC in the region. Thus, the ICPCN believes that dissemination of findings is an important component of the development of CPC globally, and increasing the evidence base is vital to improve the care provided.

ICPCN has been involved in several important research studies, many of which have been undertaken in collaboration with other organizations. A study to identify global priorities for research in CPC was undertaken using a Delphi process. Priorities for global research were identified, including children’s understanding of death and dying, managing pain where there is no morphine, funding for and the cost of CPC, training needs for CPC, and assessment of the two-step analgesic ladder. These priorities have then gone on to help form and develop ICPCN’s research strategy for the coming years.

One of the questions that ICPCN was repeatedly asked was “How many children need palliative care around the world?” What seemed like a simple question, actually posed many challenges. An initial study was undertaken in collaboration with UNICEF to identify the need for CPC in three African countries, and develop a methodology for estimating need within country, which could then be developed further to estimate global need. Following on from this ICPCN worked in collaboration with EMMS International and the True Colours Trust to identify the need for CPC in India and Malawi, which then led on to further assessment in other countries to estimate the global need. The findings of this research have been key to the development of ongoing advocacy and communication activities within ICPCN.

Other studies have included a training needs assessment, evaluation of the impact of the ICPCN training programs—both e-learning and face-to-face, a study looking at the utilization of the two-step ladder for managing pain in children in Uganda, the evaluation of the Beacon project to develop CPC in Tanzania, South Africa, and Uganda, the identification of successful models of CPC in sub-Saharan Africa, and several ongoing studies including that of looking at children’s understanding of death in dying in different countries. It is hoped that the results of all these studies will impact on the overall development of CPC globally.

Education

An important barrier to the provision of CPC has been identified as a lack of education, both for health professionals and non-health professionals, thus ICPCN recognizes the need to make training on CPC more accessible and more affordable to all who need it. Following on from a training needs assessment, ICPCN developed a two pronged education strategy—that of the provision of training through e-learning, and also through face-to-face programs.

A pilot study was undertaken to explore the feasibility of e-learning programs for CPC and their utilization globally. This was successful and so a more comprehensive program of e-learning courses has been developed, and is currently available free of charge (www.elearnicpcn.org). These programs include an introductory course, a course on the pharmacological management of pain, communicating with children, childhood development and play, end-of-life care, grief and bereavement, and perinatal palliative care. New courses being added include symptoms other than pain, and understanding the evidence. All courses are available in English, and some are available in French, Spanish, Portuguese, Serbian, Russian, Mandarin, and
Dutch. An example of how these courses can be used is in The Netherlands, where Stitching Pal—the Dutch national association for CPC, are using these programs to help prepare their volunteers and carers to support the provision of CPC around the country.

ICPCN has provided face-to-face training around the world, through sponsorship and partnering with other organizations. Thus, multi-professional training on CPC has been provided in a wide range of countries including Kenya, Brazil, Swaziland, Russia, Rwanda, Sudan, Czech Republic, Bangladesh, the Ukraine, Indonesia, the U.K., and the U.S. An evaluation of some of these training programs, both face-to-face and e-learning showed that the training had caused over 60% of individuals to change their clinical practice with over 70% showing improved knowledge, skills, and attitudes.

In line with the WHA resolution and the European Association of Palliative Care core competencies for CPC training, the ICPCN is trying to address training for individuals at both the generalist and the specialist level and are keen to support training at higher levels such as the Diploma in Palliative Care at Mildmay Uganda, and the Masters in Palliative Care (Paediatrics) at the University of Cape Town.

Training does not stand in isolation, thus funding was obtained from the Open Society Institute for Southern Africa to continue development training in Malawi and to train professionals in Swaziland, and assist the country to develop a suitable curriculum and a policy for CPC. Ongoing training on a similar model is also being conducted in Lesotho.

Strategic Development

Strategic development covers a variety of areas, including the strategic development of organizations for the provision of CPC, alongside the strategic development of ICPCN itself in terms of strategy, financing, and sustainability.

Through a program funded by Department of International Development and in collaboration with Hospice U.K., the ICPCN worked to develop CPC in Malawi and India. Working with the Indian Association of Palliative Care, national coordinators were appointed in India and Malawi, and in each country three sites for CPC were set up through the two country project—Sion Hospital HIV Clinic, in Mumbai, Jawhar, and Kalamboli. In association with the Palliative Care Association of Malawi, three sites for CPC were set up in Kamuzu in Lilongwe, Mazuzu in the north, and Zomba in the south. This successful project was multi-faceted and trained many health care professionals, reached over 3000 new children, implemented child protection policies in national associations and hospitals, trained community workers, improved access to pain medicines including morphine, and was shown to improve quality of children’s lives. Both countries produced handbooks, short films, and curricula that met the requirements of their country. National associations in both countries have CPC integrated into their strategies; and in India, a national paediatric network was established within the Indian Association of Palliative Care as a result of the project. In 2016, this has led to the establishment of a pediatric palliative care Special Interest Group within the Indian Association of Paediatrics. In Malawi, the Ministry of Health “owns” the training curriculum and is involved in training. This is a project that can be used as a model for other countries, and ICPCN hopes to develop it further in the future.

Collaboration is essential to the strategic development of CPC. ICPCN therefore has many partners with whom they work including the Maruzza Foundation, Childhood Cancer International, and a recent partnership with World Child Cancer to develop CPC in Bangladesh.

The ongoing sustainability and financing of the ICPCN is a continuous challenge. Mainly dependent on funding organizations for its sustainability, ICPCN is looking at an ongoing sustainability strategy so that they can continue to promote CPC worldwide.

The Importance of a Global Network

The ICPCN began as a simple conversation between like-minded people from different countries, and a vision of a world where all children with life-limiting conditions and life-threatening illnesses would receive the palliative care they required. At first, there were many detractors and those within the greater palliative care community who felt that a separate organization for children was not necessary. Today, even they recognize that without the ICPCN, palliative care for children would not have developed as far as it has.

The ICPCN communications strategy has led to a truly global membership and information being shared across the world. e-Learning has been done by health care workers in 115 countries, and hundreds of health care professionals in 23 countries have received face-to-face training that has led to the development of new programs for children, with partnerships have been formed to increase access and to support each other’s projects, research has led to new evidence to strengthen the case for CPC and a list of global priorities; and a number of journal articles have been written.

The focus of the ICPCN is on low- and middle-income countries which have the greatest need, but we continue to provide support to all who request
assistance as even in high income countries, children are often left behind and neglected.

“There can be no keener revelation of a society’s soul than the way in which it treats its’ children”

Nelson Mandela

References


