



STEERING GROUP

Joan Marston (Chair)
National Paediatric Manager
Hospice Palliative Care Association, SA
joan@hpca.co.za

Lizzie Chambers (Vice Chair)
Chief Executive Officer
Association for Children's Palliative Care (ACT) UK
lizzie@act.org.uk

Barbara Gelb (Vice Chair)
Chief Executive Officer
Children's Hospices UK
barbara@childhospice.org.uk

Dr Delia Birtar (MD)
Medical Director
Hospice Casa Sperantei, Brasov Romania
birtardelia@yahoo.com

Dr Julia Downing
Deputy Executive Director,
African Palliative Care Association (APCA) Uganda
julia.downing@apca.co.ug

Dr Sue Fowler Kerry
Professor College of Nursing
University of Saskatchewan, Canada
susan.fowler.kerry@usask.ca

Dr Anna Garchakova
Director
Belarussian Children's Hospice, Belarus
hospicepall@mail.belpak.by

Sue Huff
Director, Pediatrics at Home
Johns Hopkins Home Care Group, USA
shuff@jhmi.edu

Dr Rut Kiman (MD)
Chief of Paediatric Palliative Care
Professor A. Posadas Hospital, Argentina
rutiki@netizen.com.ar

Sabine Kraft
Director
National Children's Hospice Association, Germany
info@bundesverband-kinderhospiz.de

Dr Maryann Muckaden (MD)
Medical Professor Rad Onco
Tata Memorial Hospital, India
muckaden@vsnl.net

Dr Ross Drake
Clinical Director - PPC & Complex Pain Services
Starship Children's Hospital, Auckland, NZ
RossD@adhb.govt.nz

Mary Callaway (Observer)
Director
International Palliative Care Initiative
Open Society Institute (OSI) USA
mcallaway@sorosny.org

Avril Jackson (Observer)
International Information Manager, Hospice Information
Help the Hospices / St Christopher's Hospice, UK
a.jackson@helpthehospices.org.uk



LETTER FROM THE CHAIR

Dear Friends,

I recently had the privilege of reading a speech given by Bishop Kevin Dowling C.Ss.R at a graduation ceremony at the University of San Francisco on the 22 May where he

was awarded a honorary Doctorate for his untiring work for those with HIV and AIDS and those suffering from all types of social injustice in South Africa. Bishop Dowling has built up *Tapologo*, a community of love and compassion, in Rustenburg, in the North-West Province of South Africa, where there is a growing comprehensive hospice palliative care programme for children within his extensive hospice service. Bishop Dowling spoke of the need for principles and outrage – if we are truly to change the world to what it should be.

Bishop Dowling, a Bishop of the Roman Catholic Church, included in his speech words we can relate to, after describing the suffering of children dying with AIDS:

"Principle....and Outrage! Yes! Until people, and communities everywhere enter into the very personal reality of the HIV tragedy and other forms of misery, they will not feel outrage that someone, anyone, should have to suffer like this! Nor will they feel outrage at the collective and structural socio-economic systems which condemn so many of these "little ones" to a degrading life, and a lonely and hopeless death. I believe it requires that feeling of being outraged to move people to a response which should reflect a vision for humankind everywhere, a vision based on values which are deeply held in one's informed conscience, but a vision which is then guided by principles....."

"For those of us who are working to improve the right of children to receive high-quality palliative care, wherever they are in the world, may I ask the question...when did you last feel outrage at the unnecessary suffering of children and anger at the fact that we are still, after so many years of palliative care, struggling to ensure that children have at least the same access to palliative care that adults have, and that those caring for these children have the necessary knowledge and skills that are required? Or are we often so wrapped up in developing programmes and materials, and in all the necessary administrative tasks that are needed to make things happen, that we lose contact with the passion that drove us to work in this field?"

Yet, even if it is still not enough, we are doing so much and we are working together to share our experiences and knowledge, and I believe the target of all we do is the child with a life-limiting or life-threatening condition and their families. And we are making a difference, one child at a time.

A number of the steering group members were privileged to attend the European Association of Palliative Care Congress in Vienna, thanks mostly to the support of OSI, where palliative care for children was well-represented throughout the programme, and we had the opportunity to plan to work more closely with the Children's Task Team of the EAPC who share their knowledge and excellent materials so willingly. They have brought out a booklet with facts on palliative care for children that could be a resource in any part of the world.

We participated in Vienna as part of the official launch of the Worldwide Palliative Care Alliance and made a commitment to support the development of palliative care for children worldwide.

We have recently worked on the development of the African Palliative Care Association African Children's Palliative Outcome Scale, which still needs to undergo an alpha and beta piloting, and look forward to being able to measure the impact of palliative interventions on children and their families.

We are also delighted to have been invited by Dr Richard Hain to partner with Cardiff University and ACT in presenting the well-respected Cardiff Conference in 2010.

In the UK, a new True Colours Chair of Palliative care for Children has been established at Great Ormond Street and we look forward to working together in international development.

The Children's Hospice International 20th World Congress is to be held in Cape Town between 14-16 September in partnership with the ICPCN, the Hospice Palliative Care Association of South Africa, and the Tutu Institute of Prayer and Pilgrimage. The programme is exciting and covers a wide variety of issues in paediatric palliative care; we have many well-known leaders in the field attending and presenting at the congress; and the setting below Table Mountain and close to the Victoria and Albert Waterfront is stunning. We look forward to a time of learning and fellowship.

World Hospice and Palliative Care Day will be celebrated on the 10 October with the theme "Discovering your Voice". Sadly, many of our young patients have no voice. As the ICPCN we will be approaching well-known personalities to write a message of support for children requiring palliative care, to be their voice. We would appreciate any help that we can get from you, our members, in identifying well known and respected people from your part of the world who have a heart for children and who would be willing to write a message in support of children's palliative care.

Warmest greetings from a wintry Bloemfontein ... and the last challenge I will leave to Bishop Dowling.

"Nothing less than the transformation of our world, our global community, is required at this point in its history, and you have the privilege of participating in the effort required to make that happen. It will demand the interface between deeply held and lived values, a critical and searching mind, and a spirit that does not count the cost in overcoming that which diminishes or destroys hope – for example, the pillaging of the resources of our planet, the threat of climate change, wars and conflict, living in fear, extreme poverty for millions, exclusion of the "little ones" of our world from a place in the sun, the tragedy awaiting millions of our impoverished sisters and brothers because of the HIV pandemic."

Joan



Voices for Hospices is a wave of simultaneous concerts around the globe which takes place on World Hospice and Palliative Care Day every two years.

Any event that uses the voice to raise funds and awareness for World Hospice and Palliative Care Day is classed as a Voices for Hospices event. These events could be concerts from any musical genre, poetry events, drama evenings

or spoken word. The theme for World Hospice and Palliative Care Day and Voices for Hospices 2009 is "Discovering your voice".

More information and contact details for all these conferences, courses and events can be found on our website. Go to www.icpcn.org.uk

July	
3 - 4	Play Therapy UK - Play for Life
7	Young People Facing Bereavement
19 - 22	5th IAS Conference on HIV Pathogenesis, Treatment and Prevention
23	Working with children after a bereavement
30	Making the financial case for Pediatric Palliative Care - audio conference

Peterborough, Cambridgeshire, UK
 St Christopher's Hospice, London, UK
 CTICC, Cape Town, South Africa
 Dove House Hospice, Hull, UK
 Akron, Ohio, USA

September	
2- 4	HPCA International Palliative Care Conference
14 - 16	Children's Hospice International 20th World Congress
18	Hospice and Palliative Care in developing countries
22 - 25	AIDS Impact Conference
23 - 26	First Global Leadership Forum for Cancer Control
24 - 27	Together! 2009 Asia Pacific Conference & The Australian Palliative Care Conference
25	Death Anxiety

Kempton Park, Johannesburg, South Africa
 CTICC, Cape Town, South Africa
 Hinds Hospice, Fresno, CA, USA
 Gaborone, Botswana
 Ottawa, Canada
 Perth, Western Australia
 Dove House Hospice, Hull, UK



Members of the ICPCN Steering Group attend the launch of the WPCA and hold a Strategic Planning Meeting in Vienna



Standing: Dr Delia Birtar (Romania), Lizzie Chambers (Vice Chair - UK), Dr Maryann Muckaden (India), Joan Marston (Chair - South Africa), Barbara Gelb (Vice Chair - UK), Sabine Kraft (Treasurer - Germany)
 In front: Dr Ruti Kiman (Argentina), Sue Boucher (Information Officer - South Africa)

Launch of the WPCA

Tuesday 5 May marked the official launch of the Worldwide Palliative Care Alliance (WPCA), a new global action network designed to focus exclusively on hospice and palliative care development worldwide. As the children's voice on the alliance, members of the ICPCN Steering Group were invited to attend the launch. They took part in a moving ceremony where participants from around the globe made a pledge to become proactive participants in the worldwide development of palliative care for all.

Strategic Planning Meeting

Steering Group members took this opportunity to hold a Strategic Planning meeting at which the road ahead was discussed and some structural changes made to the functioning of the group. An executive board was unanimously elected with the mandate to make decisions and to hold monthly teleconferences to monitor progress of the strategic plan. Minutes of this meeting can be viewed on the website at www.icpcn.org.uk

United Kingdom

ACT launches Family Companion to help parents of children with life-limiting conditions

Authors: Lizzie Chambers and Katrina McNamara Goodger

This new publication will help families and carers of children and young people with life-limiting and life-threatening conditions understand what will happen following their child's diagnosis. A Family Companion to the ACT Care Pathway for children with life-limiting and life-threatening conditions takes parents through the care journey that they and their child will experience, step by step. ACT takes a 'Care Pathway' approach to this care journey, and this Companion is designed to dispel any feelings of confusion or isolation by explaining each stage of the ACT Care Pathway approach, in a way that is helpful and accessible to parents. It makes clear what they should expect at each stage, what they might want to think about, and who they can approach for help.

A Family Companion includes useful information about where support can be found to help parents not only understand, but get through, each stage of their child's care journey, starting with diagnosis, through the child's life, their end of life phase and the bereavement process for the whole family.

Complete with a directory of useful organisations, a comprehensive list of the health professionals that may be involved with their child, and a glossary of terms, A Family Companion acts as a handy reference tool for families when something has been mentioned that they don't quite understand, or when they are looking for a source of advice or support.

A Family Companion incorporates interactive elements to allow families to reflect and think about what they might want to happen at different stages of the pathway, and how they can make sure their wishes are fulfilled, especially at the child's end of life phase and after their death.

Free to Families

ACT will be distributing the Companion free to families of children with life-limiting and life-threatening conditions across the UK. ACT is calling upon professionals working directly with families to help distribute this new resource

Other new publications:

1. **A Guide for the development of children's palliative care services** – aimed at commissioners and providers. This is a 3rd and updated edition
2. **Right People, Right Place, Right Time** - a new resource aimed at improving the training and development of all working across children's palliative care. It covers workforce development issues and the importance of investing and retaining a highly skilled workforce.



CONTACT: Myra Johnson - PR & Communications Manager
myra@act.org.uk
 0117 916 6425

REGISTER NOW FOR THE CHILDREN'S HOSPICE INTERNATIONAL 20TH WORLD CONGRESS TO TAKE PLACE IN CAPE TOWN, SOUTH AFRICA FROM 14 - 16 SEPTEMBER



Children's Hospice International, in partnership with the International Children's Palliative Care Network (ICPCN), the Hospice Palliative Care Association of South Africa (HPCA) and with support from The Tutu Institute of Prayer and Pilgrimage are proud to bring the very first world congress dedicated to issues surrounding hospice and palliative care for children to the continent of Africa.

Registration for the Children's Hospice International 20th World Congress is open and ICPCN members are entitled to a generous discount on the fees in order to attend. The congress will take place from 14 - 16 September in the beautiful city of Cape Town, South Africa.

Links to information on accommodation and tourist sites to visit in and around Cape Town can be found on the ICPCN website.

A list of presenters and the title of their presentations is also available for download from the website. Follow the link labeled "CHI Congress" on the Home page.

Key note speakers for the congress are Sister Francis Dominica, founder of Helen House, the first children's hospice in the UK and the Reverend Doctor Joan Brown Campbell, the only woman in the clergy procession of over 200 for the enthronement of Desmond Tutu as Archbishop of South Africa. Tutu referred to her as "a woman of courage and compassion" and noted "her voice helped to bring an end to the evil of apartheid." Today, she is the first woman Director of Religion at the historic Chau-tauqua Institution, a centre for religion, the arts, education and recreation.

PEDIATRICIANS GATHER IN CALICUT, INDIA TO LEARN MORE ABOUT THE MANAGEMENT OF CHRONIC PAIN IN CHILDREN

The First State Level Workshop on Pediatric Palliative Care was conducted at the Institute of Palliative Medicine Calicut, Kerala, South India on April 26, 2009. The theme was Management of Chronic Pain in Children. It was conducted jointly by C4CCCI (Caring for Children with Cancer and Chronic Illness), the Department of Pediatrics, Medical College, Calicut and the Indian Academy of Pediatrics, Calicut Branch.

More than 70 pediatricians, both young and old attended. The workshop was inaugurated by Dr. V.K. Parvathy, President IAP Kerala. This is the first in a series that is planned on various aspects of Pediatric Palliative care, which is in its infancy in this part of the world.

Seen in the picture are Dr. V.K. Parvathy, President, Indian Academy of Pediatrics, Kerala and Dr. Suresh Kumar, Director, Institute of Palliative Medicine, Calicut



WOULD YOU LIKE TO JOIN A SPECIAL INTEREST GROUP ON PAEDIATRIC PAIN IN RESOURCE POOR COUNTRIES?

Pain management plays a major role in palliative care and is an area often neglected in developing countries. In this setting, for a variety of reasons, providing pain management for children can become compromised by a lack of resources and high patient numbers. In partnership with Dr Rene Albertyn, head of the Pain Unit at Red Cross Children's Hospital in Cape Town, South Africa, the ICPCN wishes to ini-

tiate a *Special Interest Group (SIG)* focusing specifically on paediatric pain management within developing and resource poor countries. This group will provide peer support and the sharing of information.

While we aim to bring together health professionals providing paediatric palliative care and pain management in resource poor countries, membership

will be open to anyone with an interest in this area. ICPCN members interested in joining this SIG are asked to send an email entitled: PAIN SIG to the ICPCN Information Officer at: sue@icpcn.co.za

Please supply the following details in your email:

- Name, Profession, Job Description,
- Country, town and place of work,
- E-mail address and a contact telephone number

WE HAVE LIFT OFF!

OPENING OF THE COSMOS THERAPY ZONE AT THE SHOOTING STAR CHILDREN'S HOSPICE

By Adam Petrie

Head of PR and Communications



The Shooting Star Children's Hospice

The Shooting Star Children's Hospice in south west London has recently celebrated the opening of a purpose-built therapies unit. The Cosmos Therapy Zone, which houses play, music, family and complementary therapies represents a significant development of the care services on offer.

The vision for the Cosmos Therapy Zone started after Capital Radio, a London-based radio station, chose Shooting Star as the focus of their Help a London Child Christmas Appeal in 2007. At the same time, Shooting Star had just appointed a Family Support and Therapies Team and was looking for an appropriate space and setting for their work.

“Capital Radio offered to provide funding for a play therapy room and this became the catalyst for further expansion plans,” says Dalton Leong, Chief Executive of Shooting Star. “Soon, the idea for a purpose-built therapies unit became a reality and construction began in the summer of 2008.”

The building was completed at the start of 2009 and families, staff and celebrities celebrated its launch at an official opening in March.

The care services on offer in the Cosmos Therapy Zone are evidence of Shooting Star's focus on meeting the needs of the whole family. Music and play therapies can be used by various family members, helping them to explore, express, understand and reflect on their feelings in a safe environment.



Music therapy in the CTZ zone

The new unit is also able to house counselling sessions, with Shooting Star's qualified Counselling Services Coordinator and a team of trained volunteers providing emotional and psychological support for families. The counselling service also includes pre and post bereavement support.



Shooting Star has also introduced a new service to tie-in with the launch of the Cosmos Therapy Zone. Complementary therapies, such as Indian head massage, are on offer to parents and grandparents as a way of allowing them a chance to relax. ‘Family members can be under considerable stress as they spend their time and energy caring for their loved ones,’ says Dalton. ‘The ability for them to be able to recharge their batteries is an essential part of the service we provide.’



The relaxation therapies room

The opening of the Cosmos Therapy Zone is further testament to Shooting Star's rapid growth and pioneering work. It's less than four years since Shooting Star opened its doors (the hospice was officially opened by TRH The Prince of Wales and The Duchess of Cornwall) and already supports more than 250 families. Services such as Outreach Care have witnessed significant growth in a short space of time and Shooting Star is at the forefront of effective collaborations, notably as one of the founding members of the LCHA (London Children's Hospices Alliance), which has the vision to support all life-limited children and their families in London.

‘The opening of the Cosmos Therapy Zone is another sign that we've come a long way in a short time,’ says Dalton. ‘Building a dedicated therapies unit is making a huge statement that Shooting Star takes psychological and emotional therapies seriously. Our ability to identify the needs of our families and provide for those needs through the Cosmos Therapy Zone is a great achievement but more important than our achievements is the impact the new unit will have on our families. We know from feedback we've already received that it will add considerable value to their lives.’

Shooting Star aims to help children and young people with life-limiting conditions and their families live life to the full when every moments counts and Dalton is determined the care services will continue to develop. ‘We are constantly striving to improve the service we offer and be at the forefront of innovation in the world of children's palliative care. We are forever focused on our ultimate aim – to provide more care and support to more children and families.’



The Family Therapies Room

If you wish to read more about the work and innovative programmes to be found at The Shooting Star Children's Hospice visit their website at

www.shootingstar.org.uk

by **Onica Sepuru**

Sister Onica Sepuru is a qualified palliative nurse with extensive paediatric experience. She has been working in the remote rural area of Ingwavuma in northern KwaZuluNatal, South Africa with Dr Ann Dean, who began Isibani Sethemba, previously known as *Ingwavuma Orphan Care*, in June 2000. Isibani Sethemba is a community organisation that provides physical, emotional, psychological, spiritual and economic services to the people of Umkhanyakude, KwaZulu Natal, through direct support and community mobilisation to improve their quality of life. The town of Ingwavuma is situated high in the Lebombo mountains in Northern KwaZulu Natal. Houses and homesteads are scattered over the hillside, so it is hard to say where the town starts and finishes. The organisation does not just work in the town, but spreads its services over the 3 surrounding tribal areas which cover about 2100km². It reaches in the north up to the border of Mozambique. In the South the area is bordered by the huge Pongola Dam, and the Pongola river complete with crocodiles and hippos runs northwards up its eastern boundary. The Western side of the area is the Swaziland border along the Lebombo mountain range. Isibani Sethemba is helping around 4000 orphans and vulnerable children. To learn more, visit: <http://orphancare.org.za>

The Children's Support Group was initiated by the director of Isibani Sethemba, Dr Ann Dean. It continued to grow but when she found she needed to focus more on organizational duties her time for the children's support group became limited so Dr Dean called on the help of a professional nurse with Paediatric Palliative Care experience from overseas to revive the children's support group.

We learned from her that a support group coordinator should be able to educate and train children infected with HIV/AIDS to become independent and understand more about their condition. We started a programme to develop the children's support group in collaboration with the Children's Rights Centre using one of their publications called "My Living Positively Handbook", printed by Jacana Media.

Dr Dean designed a manual to be used along with the book and to guide the facilitator of the support group.



Dr Dean discusses medications with a mother and one of her young patients.

How the sessions are run

The facilitator is always accompanied by a Health Care Professional who attends to clinical issues at the end of the session and makes recommendations for each support group.

The children are asked to bring along their "My Living Positively Handbook" to the monthly Support Group meetings. The programme starts with the song the children all know and one of them will offer to pray for us. The introduction includes each child writing how he or she feels that day.

The facilitator will then go back to the previous lesson to check the records and activities done by the children over the past month. These are done at home either with the help of a caregiver or by the child alone. As they present their work they are given small toys or they are applauded to show appreciation for their effort. We then move straight to the lesson before they lose concentration and we try to involve the children as much as possible. We ask them to tell us about their last visit to the clinic, who they saw there and whether or not they enjoyed the visit. We encourage them to tell us about the procedures carried out e.g. if blood was taken and we explain things to them so they understand that blood is needed for the CD4 count and to check their Viral Load. If they have brought their clinic cards they can look through them to find their most recent results. The facilitator has developed a song about the CD4 count and Viral Load which helps them to remember how they work together. The facilitator concludes the session, based on the topic of the day, for example, reminding them to have their blood checked every 6 months.

We then spend time looking at their clinic cards to find out the date of their next clinic visit and to do the bloods before the next support group. We may end with a happy story e.g. about a girl who is HIV positive and who is at home doing her daily work and we talk about the girl going to clinic, to school, to fetch water or to the garden for vegetables.

The materials used for the support group are inexpensive and affordable, for example we use newspapers, old magazines, crayons, safety pins, Sellotape, pens, scissors and balls.



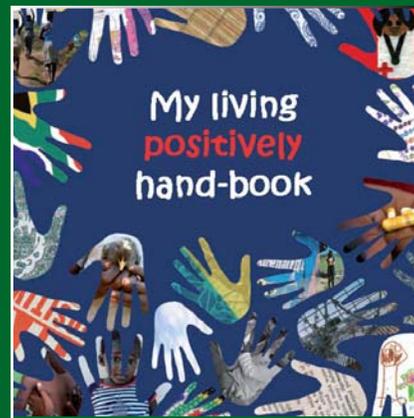
Children in the support group have fun while learning more about living positively!

If you wish to obtain an electronic copy of the manual designed by Dr Ann Dean and used by Onica at her support group, send your email request to sue@icpcn.co.za entitled: MANUAL

The children's book *My Living Positively Handbook* is a book for young children who are HIV positive.

It was made by children, families, doctors, nurses and teachers. Pictures, activities and simple information help the child to find out many ways to live positively. The book tells stories and gives children games and interesting things to do.

Helping Children living with HIV is a companion book to use with the children's book: *My Living Positively Handbook* and is written for parents, caregivers, social workers, health workers and others.



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+27 (031) 307-6075
Published by Jacana Media +27 (011) 628-3200

HIV in South Africa 'levels off'

South Africa's HIV epidemic has levelled off at an infection rate of 10.9% for those aged two or older, according to a new study.

The survey also suggests the rate of infection in children and teenagers could be falling. This could be partly attributed to increased use of condoms, it says. But the survey warned that the overall situation remained "dire". **South Africa has the world's largest HIV-positive population, at 5.5 million.**

Women aged between 20 and 34 continued to be the worst affected, with 33% carrying HIV, the report by the Human Sciences Research Council said.

Olive Shisana, an author of the study of 20,826 people, said there were "promising findings of a changing pattern of HIV infection among children and youth."

"The good news is that the change in HIV prevalence in children is most likely attributable to the successful implementation of several HIV-prevention interventions," she went on to say.

Challenges

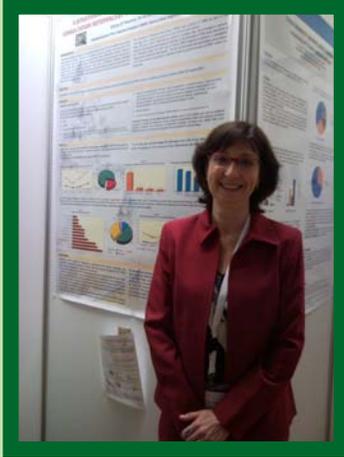
In children aged 2-14, HIV prevalence had dropped from 5.6% in 2002 to 2.5% in 2008, the report said. There was also a fall in new infections among teenagers aged 15-19.

"There is clearly light at the end of the tunnel," Aaron Mokoaleli, Health Minister. The overall level of HIV infection in those aged two and over, at 10.9%, had moved little.

For example they may write:
"My name is Onica and I feel like a *flower* today" and then the child needs to explain how being like a flower helps him or her to survive or cope.



CONGRATULATIONS TO DR RUT KIMAN



At the recent EAPC Congress held in Vienna, Steering Group member, Dr Rut Kiman's poster on research carried out by Dr Kiman and her colleagues from Argentina entitled: *A situational Diagnosis to Analyse the Reasons for Referrals for Consultation by a Paediatric Palliative Care Team*, was awarded second place in the category: Best posters from developing countries.

Dr Kiman was awarded a free personal online registration to the EJPC, the EAPC Journal for one year. The research document is to be published in the EAPC journal.

Special IQJ Subscription offer to ICPCN members

Interconnections Quarterly Journal (IQJ)

For people who work in multi-disciplinary settings with children who have disabilities and special needs
Published by Interconnections.
Edited by Peter Limbrick.

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www.icwhatsnew.com

The development of the APCA African Children's Palliative Outcome Scale

Downing J, Atieno M, Powell RA and Mwangi-Powell F

The need for palliative care service provision across Africa is significant. However, as palliative care services develop across the region, it is important to ensure that optimal quality of care is achieved. Consequently, the African Palliative Care Association (APCA) (in collaboration with King's College London [KCL], the National Hospice and Palliative Care Organization [NHPCO] and experts from six African countries) developed a simple and brief multidimensional outcome measure for palliative care (known as the APCA African Palliative Outcome Scale [POS]) using patient-level indicators to assess the quality of care during routine clinical practice (Powell et al 2007).

In developing the tool, the issue of its suitability and adaptability for use with children was considered and a plan made for the development of a POS for this target population. Consequently, and prior to the commencement of the development of the APCA African Children's POS, a literature review of existing outcome measurements in children was undertaken to build upon current research and to learn from the experiences of others. Experts from across the region were also asked about what outcome tools they use, and individuals shared experiences of using the APCA African POS with children.

A group of experts from across the region were brought together in May 2009 to draft the initial children's outcome scale. The World Health Organization's definition of palliative care for children was reviewed and participants agreed that this should form the basis upon which the domains for outcome measurement should be developed. Additionally, the ACT classes for palliative care provision were discussed to ensure that the proposed POS would be appropriate for all those requiring palliative care. Key domains were identified against which potential indicators were developed. The proposed child-level indicators cover areas such as pain and symptom management, feeding, sleeping, social interaction, crying, and playing; parent-/carer-level indicators include planning for the future, information provision, and confidence in caring for their child.

Issues of measurement, age, developmental status and communication were discussed in order to ascertain the target group for the outcome tool. It was suggested that there are two outcome scales for children: one for 'non-verbal' children, including those 3 years or younger, and one for 'verbal' children over the age of 3 years. Following discussion of adolescents, and the experience of those who have used the APCA African POS among this age group, it was felt that with minor amendments, the current APCA African POS is appropriate for use in adolescents.

for alpha piloting drafted. The protocol for piloting is being developed and ethical approval sought in the different countries where the pilot will take place. The tool will initially be piloted in South Africa, Zimbabwe, Kenya and Uganda; this will be expanded to further countries at the beta piloting stage.

The APCA African Children's POS is being developed through a collaborative process with palliative care experts from across the region, and with representation from across the multi-disciplinary team. Alongside the development of the tool, guidelines for its use will be developed and piloted to ensure that, on completion of the validation studies, the tool will be correctly and consistently used across the region.

Whilst still at the early stages of development, APCA is excited by the opportunity to develop this tool with many of its partners in Africa. It is hoped that the development of the APCA African Children's POS will be a key step in the measurement of the quality of palliative care for children across the region and will contribute to the research and evidence base for palliative care in Africa (Harding et al 2008).

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The ICPCN is part of the
Worldwide Palliative Care Alliance



Membership of the ICPCN is free and open to all who work in the field of palliative care for children. To join go to www.icpcn.org.uk

Should you wish to contribute to ICPCN Network News please contact the Editor:

Sue Boucher : Email: sue@icpcn.co.za
Cell: +27 (0)82 897 4420
P O Box 38785, Pinelands,
Cape Town, 7430
South Africa

A timeframe and step-by-step process for the development and validation of the tool has been set out and an initial tool



The ICPCN is administered from the offices of the Hospice Palliative Care Association of South Africa (HPCA) in Cape Town.
Phone: +27 (0)21 5310277
Email: hpca@iafrica.com