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Assessment of the Need for Palliative Care for Children

Three Country Report: South Africa, Kenya and Zimbabwe

November 2013

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
APCA	African Palliative Care Association
ARI	Acute Respiratory Infection
ART	Antiretroviral Therapy
ARV	Antiretroviral (Drugs)
CBO	Community Based Organisation
CHBC	Community and Home Based Care
CHOC	Childhood Cancer Foundation of South Africa
CHW	Community Health Worker
CPC	Children's Palliative Care
CSR	Corporate Social Responsibility
DoH	Department of Health
DoSD	Department of Social Development
DSS	Department of Social Services
EDLIZ	Essential Drug List of Zimbabwe

EHT	Environmental Health Technician
EoL	End of Life Care
FBO	Faith Based Organisation
FGD	Focus Group Discussion
GoZ	Government of Zimbabwe
HIV	Human Immune–Deficiency Virus
HOSPAZ	Hospice and Palliative Care Association of Zimbabwe
HBC	Home Based Care
HMIS	Health Management Information System
HPCA	Hospice and Palliative Care Association of South Africa
HRBF	Health Results Based Financing
HRH	Human Resources for Health
ICPCN	International Children’s Palliative Care Network
IMR	Infant Mortality Rate
IHME	Institute of Health Metrics and Evaluation
KEHPCA	Kenya Hospice and Palliative Care Association
KEML	Kenyan Essential Medicines List
KEMSA	Kenya Medical Supplies Authority
MDG	Millennium Development Goal
MMR	Maternal Mortality Rate
MoH	Ministry of Health (for Kenya)
MoHCC	Ministry of Health and Child Care (for Zimbabwe)
MoLSS	Ministry of Labour and Social Services
MOMS	Ministry of Medical Services
MOPHS	Ministry of Public Health and Sanitation
NAC	National AIDS Council
NCC	National Cancer Control
NCDs	Non Communicable Diseases
NGO	Non–Governmental Organisation
OVC	Orphans and Vulnerable Children
PC	Palliative Care
PCCDWG	Palliative Care Curriculum Development Working Group
PCU	Palliative Care Unit
PMTCT	Prevention of Mother–To–Child (HIV) Transmission
PSS	Psychological, Social and Spiritual
RHC	Rural Health Centre
SA	South Africa
SAHRC	South African Health Research Council
UKZN	University of KwaZulu Natal
U5MR	Under–Five Mortality Rate
UNICEF	United Nations Children’s Fund
VCT	Voluntary Counselling and (HIV) Testing
VHW	Village Health Worker
WHO	World Health Organization
WPCA	Worldwide Palliative Care Association
ZDHS	Zimbabwe Democratic and Health Survey

Executive Summary

Background: There is increasing recognition of the unmet need to provide palliative care services to children especially in low and middle-income countries. However the extent and nature of this need has not been adequately documented. There are critical gaps in the current palliative care response arising from HIV and AIDS, non-communicable diseases, complex chronic and neonatal conditions. UNICEF and the International Children's Palliative Care Network (ICPCN), in collaboration with national palliative care associations, commissioned this joint analysis to assess critical needs and gaps in children's palliative care (CPC) which is defined as care for infants, children, and adolescents from birth to age 19 with life limiting and life threatening conditions.

Methods: The assessment was conducted in three sub-Saharan countries; Kenya, South Africa, and Zimbabwe. Its aim was to analyse existing secondary data on palliative care to estimate the palliative care need amongst children and explore with service providers the key gaps in the response. The study took the form of a cross-sectional design and applied a mixed methods approach, which utilised both quantitative and qualitative data.

Estimates of the need for palliative care for children were based on country level prevalence data obtained from the Institute for Health Metrics and Evaluation (IHME) at the University of Washington (lead research group for the Global Burden of Disease Studies) and mortality data obtained from the World Health Organization's Office of Health Statistics and Informatics (Global Health Estimates). The estimation of need was based on applying a set of published assumptions and clinical knowledge to the prevalence-based estimates, and mortality based in some cases. Other data sources included UNAIDS HIV prevalence data, key informant interviews with service providers providing palliative care services in the country, stakeholders in palliative care as well as national reports and repositories. In country data collection for the three countries was undertaken from April to August 2013. A total of 49 key informants were interviewed and 31 hospice and palliative care organisations participated in the study across the three countries.

Study Limitations: A number of limitations were observed and these included 1) the reliance on secondary data sources, 2) assumptions used to adjust the estimates of need were based on past studies undertaken in settings that are different to the three countries, and 3) the subjectivity and possible respondent bias arising from the self assessment of capacity by service providers as well as the low response rate in these. Effort was made to control for data accuracy and reporting bias through triangulation and use of multiple data sources. Potential bias in the capacity self-assessment and in-depth interviews was controlled through document and records review.

Findings: HIV related illnesses and neonatal conditions are the greatest contributors to children's mortality in the three countries. Other non-malignant but chronic conditions contribute significantly to the childhood morbidity and mortality in the countries.

The need for palliative care for children is high in all the countries. There were minimal variations in this perception of the need across the cross-section of respondents. However, there appeared to be inconsistency in understanding what is included in children's palliative care. It was noted that medical staff and palliative care practitioners, particularly those who received prior training in CPC, had a more inclusive perception that considered not only HIV and AIDS, cancer and the dying but also those diagnosed with other life threatening or life limiting conditions.

The estimates of the need determined in this study indeed reflected a very high need in all of the three countries in line with the perceptions of the interviewed key persons. There are two categories that CPC fall into, one that is more general and should be met by any primary health care system, and another that is more specialised and requires additional services.

The following table summarises the estimated population need for CPC in the three countries. We distinguish between the overall need for those that can benefit from CPC from those within that group

that can be expected to have a need for specialised palliative care services. The larger group's needs should be met in the primary health care system while the latter is an indication of the real need for CPC services annually. Daily census adjusts for differences in length of time children need CPC.

Country	Generalized CPC Need	Specialised CPC Need	Population %	Rate per 10,000 Children	Average Daily Census
Kenya	660,717	264,102	0.68	120.05	72,357
S. Africa	801,155	304,441	0.62	151.92	83,409
Zimbabwe	312,046	117,231	0.91	180.63	32,118

The number of children benefitting from palliative care services in the three countries is significantly low in comparison to the estimated need. Based on the statistics provided by the NGO hospices and palliative care organisations and the estimated reach in the public facilities, the number of children reached with palliative care services in 2012 is 14,501 in South Africa (~5% of specialised need), 545 in Kenya (less than 1% of the specialised need), and 5,438 in Zimbabwe (~5% of specialised need). Thus the gap between need for and provision of specialised CPC in these countries is very large.

The low coverage was noted to be as a result of a number of interrelated factors, outlined below:

- The inadequate inclusion and focus on palliative care in policy and strategy frameworks. None of the countries have a specific policy on palliative care generally, or CPC specifically, although they are at different levels of development.
- There is a widespread lack of knowledge and adequate understanding of palliative care and CPC amongst health professionals.
- The NGOs providing specialised care to palliative care patients have a narrow targeting focus on HIV and AIDS and cancer patients, with some focusing on adult patients alone.
- Essential palliative care medications were noted to be available and recognised in the pharmaceutical supply chain of the three countries. However, in all of the three countries the reluctance of health workers to prescribe and/or administer morphine was cited as a major barrier to access to comprehensive pain management.
- Funding for palliative care services continues to be a major constraint to achieving adequate reach and quality. The NGOs and FBOs mainly depend on external donor funding to support their activities.
- The current integration efforts focus on only some elements of the health system such as service delivery, human resource training and some elements of medicine availability, with notable gaps in governance (including policy), financing and health information. Individual NGOs are focused on providing services with minimal focus on systems strengthening. In addition, the linkages in the response is weak across sectors, such as within social welfare departments.

Recommendations: In line with the above findings, the following recommendations are proffered to policy makers, service providers and funders:

- **Integration:** To address the unmet need, efforts to integrate children's palliative care within the broader health system of each country need to be increased, and a health systems strengthening approach should be taken.
- **Education:** There is a need for increased training of health workers in children's palliative care. Integration of children's palliative care into the training of all health professionals should be prioritised to facilitate numerical adequacy of palliative care skilled health workers.
- **Demand Creation:** It is essential that health providers include "demand creation" activities as part of their programmes. These primarily should focus on raising awareness and the training of community organisations to ensure the population is aware of the availability of children's palliative care services and where these can be found.
- **Funding:** It is of the utmost importance that children's palliative care is prioritised on the development agenda by funders. Palliative care plays a significant role in addressing the global development goals on HIV and AIDS, Child Health and Maternal Health.

1 Background

There are growing concerns that there are major gaps in the palliative care response to children, especially in light of the HIV and AIDS epidemic, which continues to be a major driver of mortality and morbidity along with non-communicable diseases and other complex chronic and neonatal conditions. Moreover, many children are adversely impacted by the burden of caring for parents and coping with their death, which requires psychosocial support services. Growing access to Antiretroviral Treatment, including paediatric treatment services, and extended periods of wellness has led to some changes in the nature of the palliative care services required. These changes include the management of pain and symptoms related to ARV side effects, adherence support, and management of complications associated with ongoing ARV treatment. Despite rapid increases in adult and paediatric treatment provision, with only 28% of children in need globally receiving effective HIV treatment[1], palliative care services for HIV affected children remain a priority.

It is against this background that UNICEF and the International Children's Palliative Care Network (ICPCN), in collaboration with national palliative care associations, commissioned a joint analysis to assess critical needs and gaps in children's palliative care (CPC). The assessment was conducted in three sub-Saharan countries: Zimbabwe, South Africa and Kenya and aimed to analyse existing secondary data on palliative care to estimate the palliative care need amongst children and explore with service providers the key gaps in the response.

The broad aims of the study were to:

a) Pilot a methodology developed to establish the need for palliative care for children to support more effective planning and response.
b) Provide evidence of coverage of palliative care services and service gaps in relation to palliative care for children in 3 countries, which can inform investment decisions at a country and global level.

The specific objectives are:

a) To estimate the need for palliative care amongst children in Zimbabwe, South Africa and Kenya.
b) To estimate the coverage of existing palliative care services in Zimbabwe, South Africa and Kenya.
c) To determine the service gaps[2] in relation to palliative care for children in Zimbabwe, South Africa and Kenya
d) To pilot and enhance a methodology to estimate the palliative care need and coverage of existing services that may be replicated in other countries.

This report provides an account of the process undertaken and details the findings obtained in the inquiry undertaken in the three countries. The report has five sections covering the background, summary of reviewed literature, methodology, key findings and the conclusions and recommendations.

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[1] Children and AIDS: Key Facts, Fifth Stocktaking Report, UNICEF, 2010. Accessed February 2013 at: www.unicef.org/esaro/Stocktaking_Key_Facts.pdf.

[2] Service gaps are the difference between the needs and the capacity to deliver children's palliative care services in the countries.

2 Literature Review

2.1 Definition of Palliative Care and Conditions Requiring Palliative Care

The following WHO definitions are used in the field of palliative care in guiding the targeting and service provision of palliative care services for adults and children:

a. Definition of Palliative Care

Palliative care is an active, holistic approach that improves the quality of life of patients (from the peri-natal period, through infancy, childhood, adolescence and adulthood) and their families facing the problems associated with life-threatening, life-limiting, and chronic illness; through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual[3].

b. WHO Definition of Palliative Care for Children[3]

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders:

- 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 centres and even in children's homes.

In general, palliative care is a combination of active and compassionate therapies intended to comfort and support the patient, as well as family members and other significant people in the patient's life. Palliative care is provided in an age appropriate manner using relevant therapies, tools and methods of communication and offers a support system to help patients live as actively as possible until death. It affirms life and regards dying as a normal process, intends neither to hasten nor postpone death. It is applicable in conjunction with other therapies that are intended to prolong life, such as chemotherapy, radiation therapy, or anti-retroviral therapy. It may enhance quality of life and may also positively influence the course of an illness. Palliative care essentially begins when illness is diagnosed and continues regardless of whether or not a child/patient receives treatment directed at the disease. It

- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- becomes the primary focus of care towards the end of life and in the dying process /period and
- provides support for caregivers, allowing them to work through their own reactions to the situations they encounter and the care they are providing.

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[3] World Health Organization. WHO Definition of palliative care. Accessed 30 October 2013 at: http://www.who.int/cancer/palliative/definition/en/

c. Conditions Eligible for Children's Palliative Care

There are over 360 conditions that have been identified as eligible for the provision of palliative care to children[4]. These have been categorised by ACT (now Together for Short Lives[5]) in the United Kingdom. The four Together for Short Lives Categories also summarise the diseases requiring CPC within the following domains:

1. Life threatening: may be able to be cured
2. Premature death is inevitable, but have long periods of wellness because of treatments
3. Progressive conditions where treatment is exclusively palliative
4. Irreversible but non-progressive conditions

d. Diseases Requiring Palliative Care[6]

According to the Global Atlas of Palliative Care at End of Life, the following diseases and conditions in children are considered to require palliative care: cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies, endocrine disorders, HIV and AIDS, meningitis, kidney disease, neurological disorders, neonatal conditions, and drug resistant tuberculosis.

2.2 Previous Studies and Gaps in Literature

There is a general paucity of information regarding the actual need for palliative care specifically for children. Although there have been some studies focusing on the status of CPC in South Africa and sub-Saharan Africa, there are differences in the scope and approach to the present study.

Some of the previous studies place a focus on exploring the needs of children requiring palliative care as well as the existing levels of support, but not necessarily focusing on estimating the magnitude of the need. Clearly, these studies play a complementary role and have provided a sound framework and justification for efforts to establish the extent of the need. Of note is the study on the Status Of Paediatric Palliative Care in sub-Saharan Africa - An Appraisal[7]. This study aimed to systematically identify and appraise the evidence for CPC in sub-Saharan Africa, in order to identify best practice and effective models of care and to inform the development of the discipline. The key findings of this study were that despite the high prevalence of HIV and rising incidence of cancer, particularly among the paediatric population, there has been little progress in palliative care service provision in comparison to that of adult palliative care. In addition there are very few documented models of care, limited evidence for quality CPC, which is largely attributed to the absence of validated tools for outcome measurement, and generally a limited body of literature describing the contextualised meaning and management of terminal illness in children.

Other complementary studies and publications include Children's Palliative Care in South Africa - The Facts[8] and the programme level report, Survey on Paediatric Palliative Care in South Africa[9]. These studies provide the context of the need for palliative care for children by explicitly outlining the needs of children requiring palliative care. The studies identified gaps in CPC service and prioritised training and mentorship of care providers (including health workers), holistic care provision, a multi-disciplinary team approach and advocacy for inclusion in national health priorities.

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[4] Hain R, Noyes J, Devins M, Hastings R. *Paediatrics* - Development of a 'Dictionary' of life-limiting conditions to explore epidemiology of life-limiting conditions in children.

[5] Together for Short Lives is a leading UK charity for children with life-threatening & life-limiting conditions

[6] Connor S and Sepulveda C (Editors) (2013 In-Press) *Global Atlas of Palliative Care at the End-of-Life* . Worldwide Palliative Care Alliance and World Health Organization: London UK, Geneva CH

[7] Harding R, Sherr L and Albertyn R. Status Of Paediatric Palliative Care In Sub-Saharan Africa - An Appraisal. 2010

[8] Children's Palliative Care in South Africa - The Facts. ICPCN. 2010

[9] Survey on Paediatric Palliative Care in South Africa. HPCA. 2012 (Unpublished)

The Global Atlas of Palliative Care at the End of Life presents a robust methodology in estimating the need for palliative care but due to its focus, the approach is limited to end of life care. The report, however, indicates that children aged 0-14 years constitute 6% of the global palliative care burden at the end of life, estimated at nearly 1.2 million. The estimation of the need was based on mortality data. Other approaches to estimate the need have been used elsewhere such as the New Zealand[10] model outlined below.

Palliative Care Estimation - Population Of Patients With A Life-Limiting Or Life-Threatening Condition (adapted from Palliative Care Australia, 2005).

- Group A - consists of people who will require care at the end of life, but the level of care they need can be provided by their primary team, so long as the team is appropriately prepared and resourced to provide palliative care as a part of their standard clinical practice. This level of care is referred to as primary palliative care.
- Group B - experience sporadic exacerbations of symptoms and problems that will require temporary access to specialised palliative care services for consultation and advice.
- Group C - people with complex end of life care needs who will require direct ongoing care from a specialised palliative care service. This group may still receive some care and support from their primary team as well.

The size of each group is not easily determined, however using figures suggested by Palliative Care Australia (2003), a very broad estimate may be:

- Group A – 10% of cancer deaths and 60% of non-cancer deaths, which is equivalent to 41.4% of all deaths.
- Group B – 70% of cancer deaths and 30% of non-cancer deaths, which is equivalent to 39.8% of all deaths.
- Group C – 20% of cancer deaths and 10% of non-cancer deaths, which is equivalent to 12.3% of all deaths.

Generally studies that have estimated the need for palliative care for children are based on mortality and morbidity statistics for chronic, incurable illnesses. Most of these estimates are also based on end of life care, including bereavement support. This method of estimating the need for CPC has a gross limitation of failing to reflect the whole spectrum of palliative care which ideally should begin with diagnosis, as it simply gives an estimate of the need for improved end of life care, including bereavement. Available literature attempting to estimate the need for children's palliative have focused mainly on children living with HIV and cancer, neglecting other relevant conditions.

One exception to this limitation is a study from the UK[11] that has determined that the population prevalence for children 0-19 with life limiting conditions needing specialised palliative care is 32 per 10,000 children in England. We use this reference point as a comparator making the observation that, due to higher HIV/AIDS incidence and lack of access to well functioning health care systems in sub-Saharan Africa, we would expect that the population prevalence will be considerably higher than in a developed country such as England. In the results section of this report you will see a rate per 10,000 children for each country that is consistent with this assumption.

In addition, the World Health Organization Collaborating Centre for Palliative Care and Public Health in

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[10] National Health Needs Assessment for Palliative Care, Phase 2 Report, PCC New Zealand, 2012

[11] Fraser L, Miller M, Hain R, Norman P, Aldridge J, McKinney P, Parslow R: Rising national prevalence of life-limiting conditions in children in England**.** *Pediatrics* 2012, **129**(4)**:**923.

Barcelona, Spain has published population estimates for the need for palliative care in Spain. Their estimate is for adults and projects that at least 1.5% of the country's population will need specialised palliative care services at a given point[12]. In our results we also show the population percent as a further point of reference to support our findings.

3 Methodology

This study identifies children as infants, children, and adolescents from birth to 19 years of age. The rationale is that children are living longer with life threatening conditions acquired in childhood and to limit the study to an earlier age cut off would underestimate the need for CPC. This section describes the methods used to determine which children will need palliative care from among the many children that have a serious illness but whose life span is likely to be normal. In addition, the methods used to determine the capacity to deliver CPC in each of the focus countries are described. CPC in this study refers to the delivery of specialised palliative care services, which may or may not be delivered by health professionals qualified as specialists in children's palliative care.

3.1 Study Design

The study took the form of a cross-sectional design with a focus on estimating the need for CPC and gaps at the country level. A mixed methods approach utilising both quantitative and qualitative data was used. Both primary and secondary data sources were used. The estimation of the need for CPC was based on estimation techniques using the prevalence and mortality of the specific diseases known to require palliative care. The response to the need and existing gaps were analysed using data obtained from literature review, interviews with key persons as well as survey data from service providers.

3.2 Study Location, Study Population and Reference Population

This study was conducted in three sub-Saharan African Countries, namely Kenya, South Africa and Zimbabwe as indicated on the map on page 20 / Figure 5. These countries were selected based on data availability, strength of networks, regional diversity and priority countries for children's palliative care services. Country level disease prevalence data for each of the identified conditions requiring palliative care was obtained from the Institute for Health Metrics and Evaluation (IHME) at the University of Washington (lead research group for the Global Burden of Disease Studies). Mortality data was obtained from the World Health Organization's Office of Health Statistics and Informatics (Global Health Estimates). Other data sources included UNAIDS HIV prevalence data, service providers providing palliative care services in the country, stakeholders in palliative care as well as national reports and repositories. The findings of this study are inferable to CPC needs and services in Kenya, South Africa, and Zimbabwe as well as providers of CPC in the countries.

3.3 Ethical Considerations

- Ethical clearance for this study was sought from the HPCA International Review Board (IRB) and from in-country review boards for Kenya (Kenya Medical Research Institute - KEMRI) and Zimbabwe (Medical Research Council of Zimbabwe - MRCZ).

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[12] Gómez-Batiste X, Martínez-Muñoz M, Blay C, et al. Identifying patients with chronic conditions in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia. BMJ Supportive and Palliative Care 2012;0:1–9. doi:10.1136/bmjspcare-2012-000211.

- All ethical aspects for consideration in research involving human subjects were upheld, including informed consent to participate and anonymity. All interviewed participants completed consent forms for participation and audio recording.

3.4 Sampling Strategy and Sample Size

A combination of sampling approaches was used for the different groups.

a. For the quantitative aspect of the study, all children fitting the inclusion criteria of requiring palliative care (all infants, children and adolescents having one or more conditions listed in Table 3 as agreed by WHO) were included in the estimation of the need for palliative care.. No sampling was undertaken for this group.
b. Purposive sampling was used to identify key persons for in-depth interviews. The main characteristic of interest in the targeting was their involvement in children's palliative care service provision. Practitioners in the public sector and serving hospices/palliative care organisations were targeted. The target sample size was 15 key persons. A total of 49 individuals across the three countries, among them palliative care experts and service providers, were interviewed in the study.
c. All organisations providing palliative care services for children in Kenya, South Africa and Zimbabwe were targeted for a survey to assess service provision and capacity. A list of 53 eligible organisations in the three countries was developed.

3.5 Outcome and Study Factors

The following case definition for Children's Palliative Care was used in this study:

Care for infants, children, and adolescents with life threatening and life-limiting conditions as described by the WHO definition of palliative care for children.

The outcomes of interest in this study were 1) an estimate of the need for CPC 2) the response to need and the capacity of service providers. The capacity of service providers was assessed to establish the gaps in the current response. A Health Systems Assessment (HSA) approach was used in assessing capacity. This study therefore considered capacity in the context of organisational or system capacity with domains guided by the WHO Pillars of the Health System and WHO Public Health Model for Palliative Care. Five domains of capacity assessment were derived from these two frameworks: Policy and Strategy, Service Delivery (Package of Care), Human Resources (Numerical Adequacy, Training/Education), Pharmaceuticals and Financing of Palliative Care Activities. The CPC need, response and capacity were assessed in the context of the following study factors:

Table 1: Outcome and Study Factors for Analysis of Need in Children's Palliative Care Provision

Outcome Factor	Study Factors
Estimated need for CPC	Disease/condition, age group, sex
Response	Disease/condition, age, type of organisation
Capacity	Type of organisation, level of service delivery

In addition to the quantitative assessments of these factors, the perceptions and opinions of service providers and stakeholders were obtained to triangulate and provide a comprehensive picture of the need, current response and capacity of service providers.

3.6 Data Sources

Three data sources were used to determine the need for CPC.

1. Country level prevalence data from the Institute for Health Metrics and Evaluation (IHME) at the University of Washington. This was the only source for prevalence data for most of the identified conditions.
2. World Health Organization mortality data from the Global Health Estimates. Causes of Death 2000-2011. www.who.int/healthinfo/global_burden_disease/en
3. UNAIDS data on HIV prevalence in the target countries.
4. Country level data collection, interviews, and surveys.

3.7 Data Collection Methods and Tools

A variety of methods and tools were used to obtain the data for this analysis:

a. Data Extraction: Prevalence and mortality data for specific disease conditions (outlined in Table 3) from WHO Global Health Estimates Study data repository and from the IHME database were used in estimating the need for CPC.

b. In-depth interviews were conducted with identified key persons. As noted earlier, the selection of key informants was purposive based on a consultative process in which in-country known palliative care experts, ministry officials, representatives of the national hospices and palliative care organisations suggested key persons for interview. With the aid of a Key Informant Interview Guide (see Appendix 1) developed for the purpose, in-depth interviews were held with key persons providing palliative care services in each country as well as other stakeholders involved with palliative care service provision. The guide was structured in line with the WHO Public Health Model for palliative care and WHO pillars of the health system. Specific domains of inquiry were therefore: Policy and Strategy, Service Delivery, Human Resources, Pharmaceuticals and Financing of Palliative Care Services. The interviews were conducted face to face and took an average of one hour and 15 minutes.

c. Organisation Capacity Self-Assessment: Organisations that were identified through the national organisations as providing palliative care for children were all requested to complete a Capacity Self Assessment Tool developed by the African Palliative Care Association (APCA) and to return them within two weeks. Guidance was provided as to who should complete the assessment tool (mainly clinical staff) although it was up to the organisation to choose the person or team to do so. The tool (attached in the Appendix) has been validated and has specific domains of care in palliative care, which are Holistic Care Provision, Pain and Symptom Management, Psychosocial Care, End of Life Care and Bereavement Care. Organisations were requested to rate, on a Likert Scale, their status with respect to specific indicators falling under each domain. A total of 36 organisations in South Africa, 12 in Kenya and 11 in Zimbabwe were listed and were sent questionnaires for completion. Of these 20 (56%), 5 (45%) and 6 (50%) organisations responded. The country visits provided a platform to follow-up on the returns. The main reasons that were identified for the low response rate were that for most organisations, their focal persons or team members were not available or had other commitments during the data collection period. Other organisations did not respond to the survey communication. The findings are however reflective of the situation of the organisations as the participating organisations exhibited a mix in terms of both scale/size of operations as well as geographical spread. In addition, the in-depth interviews helped in triangulating information.

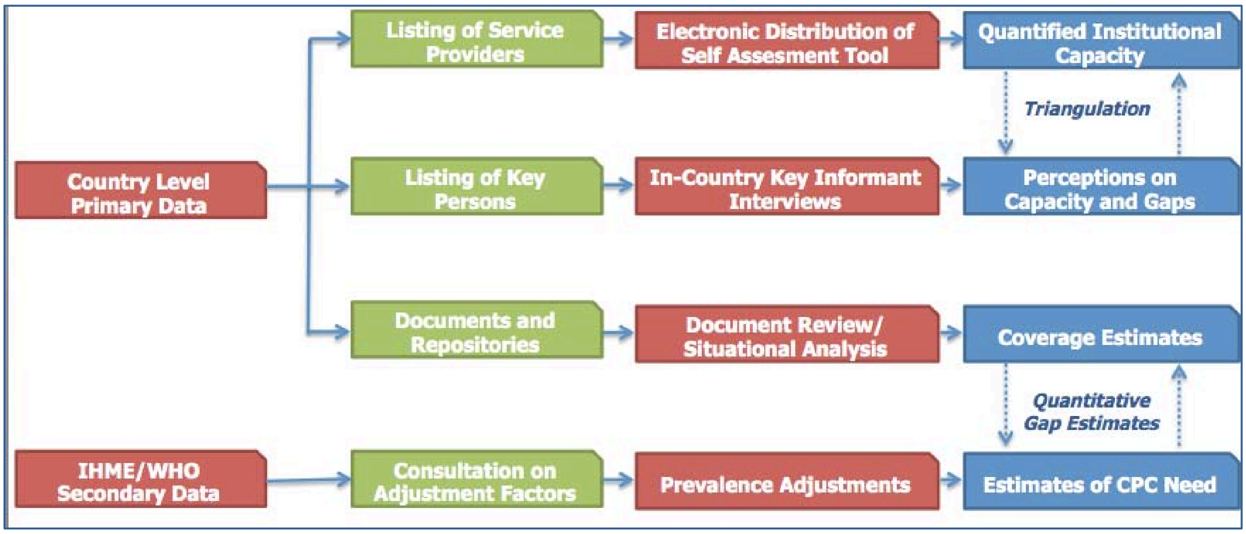
In-country data collection for the three countries was undertaken during the following period: South Africa (April 10-21), Kenya (24 July-03 August) and Zimbabwe (15 August - 30 August).

3.8 Data Analysis

A database to capture organisational capacity assessment survey data was developed in Epi Info. A descriptive analysis of the capacity scores obtained through the APCA Paediatric Palliative Care Assessment Tool was undertaken to provide a quantitative picture of capacity of the service providers and self-reported progress towards performance excellence. In addition to the scores, qualitative data on the informants' perceptions of barriers was analysed using NVivo Software. Coding was done in the software by specifying themes and sub-themes as outlined in the KII guide and drawn from the reviewed literature study. Factors such as country and type of respondent were also coded to allow for stratified analysis. Data on coverage was collated and was compared with the estimated need in order to provide an estimate of the size of the unmet need or gap.

Data on need for palliative care was analysed in Microsoft Excel (See appendix 2 for a copy of the excel data sheet summarizing all the results). IHME provided excel files for all the requested conditions. Those sheets included each diagnosis for each country with sequela for each diagnosis and an age breakdown as follows: 0-6 days; 7-27 days; 28-364 days; 1-4 years; 5-9 years; 10-14 years; 15-19 years. Totals were generated for each condition by country and entered into the summary table where adjustments were made (see 3.8 below).

Figure 1: Flowchart: Primary (Country Level) and Secondary Data Collection



3.9 Prevalence Data Modifications for Palliative Care

3.9.1 Assumptions Used in Data Modifications

The methods developed for determining the need for CPC were applied to each country identically. We began with the list of diagnostic groups that needed CPC. This list (below) was initially determined using experts in CPC but was modified in discussions with WHO Department of Health Statistics and Informatics. Many of the assumptions applied here were agreed to in a parallel publication *Atlas of Palliative Care at the End of Life*[5] developed in partnership with WHO Collaborating Centres on Palliative Care and currently under final review at WHO Headquarters. In several diagnostic groups mortality was used in place of prevalence due to the nature of the condition, as indicated in Table 3 below.

Since not all those within a prevalent condition would need palliative care at a given point in time we used symptom burden, especially pain, as an indicator for palliative care. Pain in progressive non-malignant conditions is reported to occur at an average rate of 67%, which was used as the adjustment factor for symptom burden in this study and to be consistent with the Atlas of Palliative Care at the end of life[13]. Further, we eliminated specific sequelas that were not consistent with life threatening or life limiting conditions. These adjustments to the prevalence data are outlined below:

Table 2: Assumptions and Modifications of Prevalence Estimates used in CPC Health Conditions

Condition	Adjustments and Assumptions
All Cancers	• All cancers included except non-melanoma skin • Symptom factor for childhood cancers is 80%[13] • Prevalence data from IHME
HIV/AIDS	• All categories except HIV pre-AIDS Asymptomatic • Symptom factor 60%[13] • Prevalence data from UNAIDS
Progressive Non-Malignant Diseases	• Symptom factor for all PNMD's is 67%[13]
Cardiovascular diseases	• Prevalence data from IHME • Sudden deaths removed (33%[14]) before application of the 67% symptom prevalence rule. • Excludes o Acute myocarditis o Atrial fibrillation and flutter o Endocarditis
Cirrhosis of Liver	• Prevalence data from IHME • Includes all causes/sequel
Congenital Anomalies	• Prevalence data from IHME • Includes: o Neural tube defect o Congenital heart anomalies (50%[15]) o Heart failure due to congenital heart anomalies o Chromosomal unbalanced rearrangements o Other congenital anomalies • Excludes o Cleft lip and palate o Down's syndrome o Turner's syndrome o Klinefelter syndrome o Hearing loss due to congenital anomalies
Endocrine, blood, & immune disorders	• Prevalence data from IHME • Excludes most anaemia's except o Sickle cell, Thalassemia, Fanconi's, Aplastic
Meningitis	• Based on WHO mortality data not prevalence
Kidney diseases	• Prevalence data from IHME • All causes
Protein Energy Malnutrition	• Based on WHO mortality data not prevalence
Neurological conditions	• Based on WHO mortality data (higher than prevalence data) • Includes

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[13] Higginson, I J. Palliative and Terminal Care Health care needs assessment: The epidemiologically based needs assessment reviews. In A. R. Stevens, J. Oxford and New York, The Wessex Institute for Health Research and Development, 1997.

[14] The 33% figure is used to be consistent with the Atlas of Palliative Care. Sudden death from CVD is estimated to be one third of cases based on Centres for Disease Control reports.

[15] Many children with congenital heart anomalies die suddenly without symptom burden. The 50% figure is used to be consistent with assumptions used in the Atlas of Palliative Care.

	o Alzheimer’s and other dementias o Parkinson’s and Multiple Sclerosis o Other neurological conditions (Guillain-Barré Syndrome) • Excludes o All epilepsy o All migraine and headache • All other neurological disorders
Neonatal conditions	• Prevalence data from IHME • Includes o Most preterm birth complications for 0-9 year olds[16] o Impairment due to neonatal encephalopathy for 0-9 year olds - birth asphyxia and birth trauma (75% of these are removed due to WHO position that these can be resuscitated). • Excludes o 25% out of the 35% of pre-term babies that die on the day of birth[16] o Retinopathy of prematurity due to preterm birth complications o All sepsis and other infections of newborn babies • Other neonatal disorders
Tuberculosis (1.417% DR-TB)	• Based on WHO Stop TB mortality data, not prevalence • Only includes children with MDR or XDR-TB o Calculation of 1.417% of mortality is based on the global proportion of TB prevalence that is drug resistant (170,000 drug resistant out of 12 million prevalence)

The four diagnostic groups where mortality was used in place of prevalence were meningitis, protein energy malnutrition, neurological conditions, and DR-TB. The main reason for using mortality was that three of these conditions were potentially reversible and there was also a high degree of suffering. In neurological conditions the data indicated that mortality was actually higher than prevalence, thus providing a more accurate statistic.

To account for the fact that some children will need palliative care for as short a time as one day while others may need care for 365 days in a given year, we use an Average Daily Census (ADC) figure to account for survival in the group of children that will need CPC in a given year. ADC is calculated by applying an average length of service (ALOS) to the population of children needing CPC. Adult ALOS in specialised palliative care is approximately 70 days. A recent report[17] estimates that ALOS for children is at least 1.4 times that of adults. So for this study we used an ALOS of 100 days for CPC need. We multiply the number of children needing specialised CPC by 100 and divide by 365 to calculate the ADC.

3.9.2 Specialised vs. Generalised Palliative Care

To understand the need for palliative care in a given country, it is important to distinguish between those children where a palliative approach by community health care providers should be adequate to meet their needs and children with more complex symptom burdens who need more specialised palliative care. There are varying opinions about what percentage of children or adults with a life limiting condition will need specialised palliative care. Available data and published evidence vary considerably, depending on the setting and available health care resources in a country. In developed countries like the United Kingdom or Germany it may range from 10-20% of patients, while in developing countries it may be considerably higher. For this report we have estimated the need for specialised services at 37.5%, which is from population estimates and recommendations from Australia where the most work

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[16] WHO reports that 35% of children die on the day of birth and does not consider most to need palliative care. We removed 25% of these cases but 10% were retained to be consistent with the Atlas of Palliative Care Assumptions to account for children that where we know they will die shortly after birth.

[17] Australian Government Institute of Health and Welfare. Trends in Palliative Care in Australian Hospitals. Accessed 30 Oct 2013 at: http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCgQFjAA&url=http%3A%2F%2Fwww.aihw.gov.au%2FWorkArea%2FDownloadAsset.aspx%3Fid%3D10737420164&ei=fOJxUseDE8OftAb_tIGwBQ&usg=AFQjCNFzPK751v6lTgUcf8C4r4dYsZx_OA&bvm=bv.55819444,d.Yms&cad=rja

has been done on population based palliative care needs[18]. Those needing specialised palliative care are then shown as a percentage of the total population and as a rate per 10,000 children in the population.

3.9.3 Steps in Data Modifications

The steps in the data modification were then as follows:

1. Begin with country level prevalence data for the identified conditions.
2. Remove sequelae that do not require palliative care.
3. Use mortality in place of prevalence for selected conditions.
4. Adjust for symptom burden (pain as a surrogate marker for CPC need) 67% of total adjusted prevalence.
5. Adjust for need for specialised PC (37.5%).
6. Calculate average daily census to account for survival using an average length of service of 100 days.

Table 3: Example of How to Estimate the Number of Children in Need of Palliative Care

Condition	Country Level Prevalence for Identified Condition	Sequelae Not Requiring Palliative Care	Prevalence (Excluding Sequelae Not Requiring PC	Symptom Burden (%)	Adjustment for Symptom Burden	Adjustment for Specialised Need
Life Threatening or Limiting Condition	A	B	C = A - B	D	E = C x D	E x 37.5%
Example:						
Congenital Anomalies in South Africa	390,000	196,592	193,408	67%	129,583	48,594

Note: In the example above, the prevalence of 193,408 includes neural tube defects, congenital heart defects, heart failure due to congenital heart, chromosomal unbalanced rearrangements, & other anomalies. The sequelae that are not included are cleft lip/palate, Downs Syndrome, Turner and Klinefelter syndromes, and hearing loss.

4 Findings

4.1 Contextual Analysis

South Africa and Zimbabwe are located in the southern region of Africa whilst Kenya is situated in the north-east of the continent. The three countries are at varying levels of economic growth, with GDPs of 37.3 billion for Kenya, 384.3 billion for South Africa, and 10.8 billion for Zimbabwe. South Africa is regarded as a middle-income country whilst Kenya is considered to be the hub of the north-eastern region in terms of development. Zimbabwe is currently on a recovery path after a decade of economic crisis. The countries share similarities in the sex and age distributions of their populations. Females constitute nearly half of the population and the majority are children and young people under the age of 30 years. Despite some similarities, South Africa has progressed more than the others in response to

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[18] Palliative Care Australia. A guide to palliative care service development: A population based approach. 2005 At: http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&ved=0CCkQFjAA&url=http%3A%2F%2Fwww.palliativecare.org.au%2FPortals%2F46%2FA%2520guide%2520to%2520palliative%2520care%2520service%2520development%2520%2520a%2520population%2520based%2520approach.pdf&ei=DEBLUsDKLYe_qQG3moDoAQ&usg=AFQjCNFin-cN4E09xn5pESmpuULExQZC5g&bvm=bv.53371865,d.aWM

need with a national comprehensive social protection programme and in some areas, stronger health systems.

The three countries have continued to face challenges related to the protracted effects of HIV and AIDS. Despite a notable decline in the adult HIV prevalence in the countries, the current prevalence estimates of 17.9%, 6.1% and 14.7% for South Africa, Kenya and Zimbabwe (UNAIDS, 2012 Estimates) respectively are still regarded as high and point to a significant HIV and AIDS burden in each country. South Africa is regarded as having the largest HIV and AIDS burden in the world[19]. The HIV burden in the three countries is compounded by TB co-infection. Co-infection rates exceed 70%, with TB being the most common opportunistic infection among them[20,21].

The following table provides a summary of the demographic and HIV epidemiological profiles of the three countries.

Table 4: Demographic and HIV Epidemiology Summary for South Africa, Kenya and Zimbabwe

Indicator	South Africa	Kenya	Zimbabwe
Country Population (Based on Latest National Censuses)	49.3 Million	38.6 Million	12.9 Million
Number of people living with HIV	6,100,000 (5,800,000 - 6,400,000)	1,600,000 (1,600,000 - 2,,000,000)	1,400,000 (1,300,000 - 1,500,000)
Adults aged 15-49 years prevalence rate	17,9% (17.3% - 18.4%)	6.1% (5.9% - 6.3%)	14.7% (13.8%, 15.6%)
Adults aged 15 and up living with HIV	5,700,000 (5,500,000 - 6,000,000)	1,400,000 (1,400,000 - 1,500,000)	1,200,000 (1,100,000 - 1,300,000)
Women aged 15 and up living with HIV	3,400,000 (3,200,000 - 3,600,000)	820,000 (790,000 - 860,000)	700,000 (660,000 - 740,000)
Children aged 0-14 living with HIV	410,000 (370,000 - 450,000)	200,000 (180,000 - 240,000)	180,000 (160,000 - 200,000)
Deaths due to AIDS	240,000 (220,000 - 270,000)	57,000 (51,000 - 65,000)	39,000 (34,000 - 45,000)
Orphans due to AIDS (0-17)	2,500,000 (2,300,000 - 2,700,000)	1,000,000	890,000 (810,000 - 980,000)

Source: UNAIDS HIV and AIDS Estimates, 2012

South Africa recorded a total of 543,856 deaths in 2010[22], 91% of which were due to natural causes. The ten leading underlying natural causes of death between 2008 and 2010 in order are Tuberculosis, Influenza and Pneumonia, Intestinal Infectious Diseases, Other forms of Heart Disease, Cerebrovascular Diseases, Diabetes Mellitus, HIV, Hypertensive Diseases, Chronic Lower Respiratory Diseases and Other Viral Diseases. The neonatal, infant and under five mortality rates for 2011 were estimated at 35, 47 and 19 per 1,000 live births respectively.

An estimated 56,485 children died due to natural and non-natural causes in 2010. HIV and Tuberculosis were ranked the 9th and 5th leading causes of death amongst children aged 0-14 years respectively. Similarly, diseases in the perinatal period and those relating to length of gestation and foetal growth were ranked 6th and 7th. Respiratory and cardiovascular disorders accounted for 43% of neonatal deaths.

In Kenya, the neonatal, infant and children under 5 mortality rates were estimated to be 26.8, 48.7 and 72.9 per 1,000 live births in 2012. According to the Kenya Demographic and Health Survey 2008/2009,

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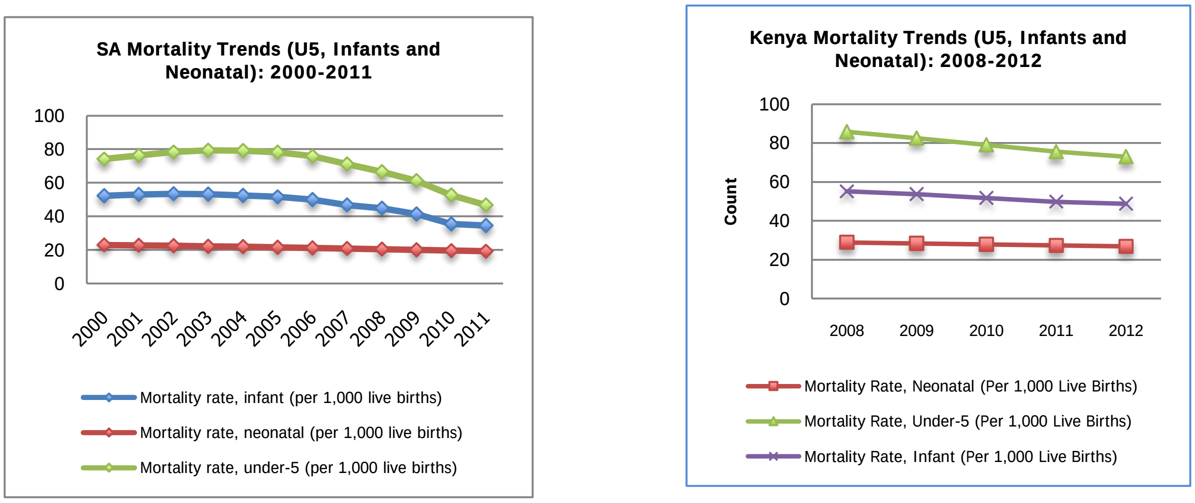
[19] South Africa's Children - A Review of Equity and Child Rights, South African Human Rights Commission/UNICEF, 2010
[20] SA Millennium Development Goals Country Report, 2010
[21] Zimbabwe Millennium Development Goals Country Report, 2012
[22] Mortality and causes of death in South Africa, 2010: Findings from death notification

at least 60% of the infant deaths in Kenya occur in the neonatal period. Diarrhoea, Malaria, Pneumonia and HIV and AIDS are the major causes of death amongst children under 5 years.

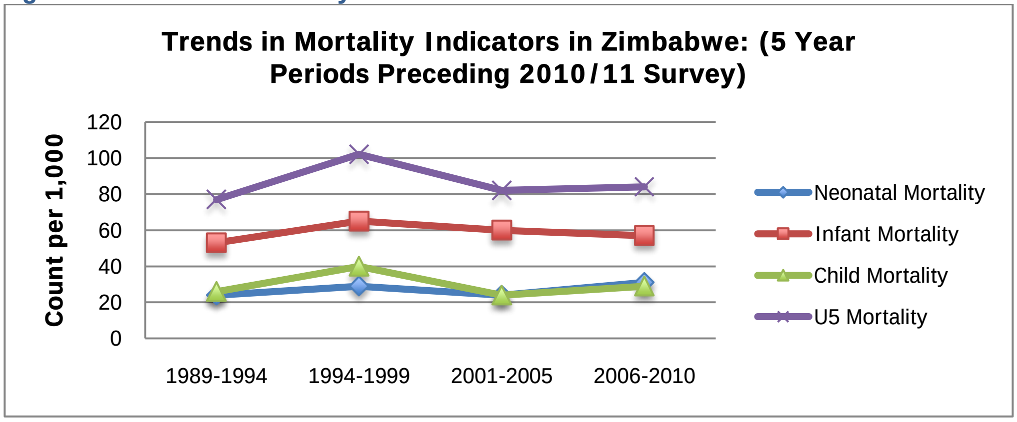
Figure 2: Children's Mortality Trends in South Africa and Kenya



Source: World Development Indicators, World Bank, 2013

The leading causes of morbidity and mortality in Zimbabwe are Acute Respiratory Infections (ARI) (Lower Tract), HIV related/AIDS, TB and intestinal infections with each contributing 12.5%, 1.7%, 9.3% and 7.5% respectively. The 2010/11 ZDHS estimated the neonatal, infant, child and under 5 mortality rates at 25, 46, 17 and 62 per 1,000 live births respectively. The estimates mark a decline from previous years as shown by the graph below. At least 41% of the U5 Mortality Rate is attributed to HIV/AIDS as the underlying cause and 26% of the Maternal Mortality Ration (MMR) is attributable to HIV/AIDS.

Figure 3: Children's Mortality Trends in Zimbabwe



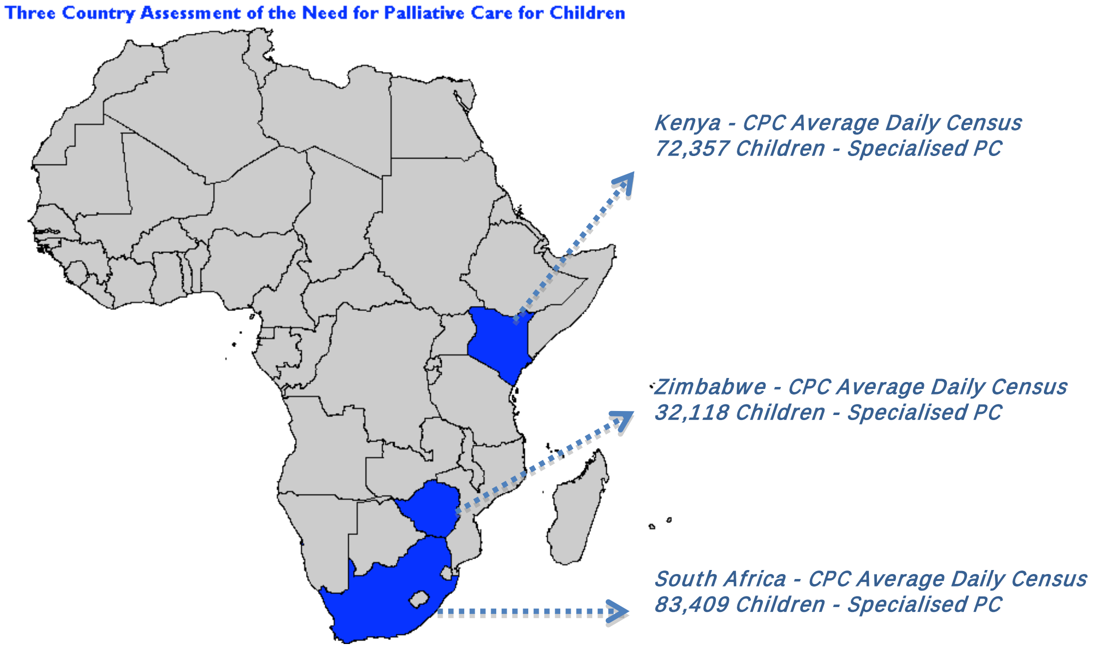
4.2 The Need for Children's Palliative Care

4.2.1 Estimates of the Need for Children's Palliative Care

The analysis based on the methodology outlined in **Chapter 3**, estimates 801,155 children require generalised palliative care in a given year and of these, 304,441 would require specialised palliative care in South Africa. For Kenya and Zimbabwe, the estimated number of children in need of generalised palliative care is 680,717 and 312,046 respectively whilst those in need of specialised palliative care are estimated at 264,102 and 117,231 respectively.

The modelling also shows that the average daily census estimates of children in need of specialised palliative care are 72,357 (Kenya), 83,409 (South Africa) and 32,118 (Zimbabwe).

Figure 4: Children in Need of Palliative Care in Kenya, South Africa and Zimbabwe



Three Country Assessment of the Need for Palliative Care for Children

Kenya - CPC Average Daily Census
72,357 Children - Specialised PC

Zimbabwe - CPC Average Daily Census
32,118 Children - Specialised PC

South Africa - CPC Average Daily Census
83,409 Children - Specialised PC

The main contributor to the estimated burden in the three countries is cardiovascular disease, which has been estimated to be about 26%, 42% and 32% of the broad need in South Africa, Kenya and Zimbabwe respectively. Its contribution to the specialised need was noted to be somewhat similar. Respectively, the collective contribution of all progressive non-malignant diseases, including cardiovascular, is very high at about 55%, 75% and 54% for the generalised palliative care. When compared to the estimated need for children's palliative care in the United Kingdom, the rates of need are 3.75 higher in Kenya, 4.75 times higher in South Africa, and 5.6 times higher in Zimbabwe. The estimates are summarised in the tables below.

Table 5: Estimates of the Need for Children's Palliative Care in South Africa

Diagnosis	Prevalence 0-19	Symptom Adj. Factor	Estimated CPC Need	Specialised CPC Need	Mortality
All Cancers	5,314	0.8	4,251	4,251	712
HIV/AIDS	600,000	0.6	360,000	135,000	12,657
Progressive Non-Malignant Diseases					
Cardiovascular diseases (.67)	312,576	0.67	209,426	78,535	1,207
Cirrhosis of Liver	363	0.67	243	91	120
Congenital Anomalies	193,408	0.67	129,583	48,594	4,627
Endocrine, blood, & immune disorders	81,833	0.67	54,828	20,561	1,422
Meningitis	626	0.67	419	157	626
Kidney diseases	18,018	0.67	12,072	4,527	286

Protein Energy Malnutrition	1,406	1	1,406	1,406	1,406
Neurological conditions	347	1	347	347	347
Neonatal conditions	42,044	0.67	28,169	10,564	16,763
Tuberculosis (1.417% DR-TB)	409	1	409	409	409
TOTAL	1,256,344		801,155	304,441	40,582
Population Prevalence (All Ages)			1.62%	0.62%	
Rate/10K			399.78	151.92	
Average Daily Census				83,409	
%of Need Met				4.76%	

Table 6: Estimates of the Need for Children's Palliative Care in Kenya

Diagnosis	**Prevalence 0-19**	**Symptom Adj. Factor**	**Estimated CPC Need**	**Specialised CPC Need**	**Mortality**
All Cancers	2,653	0.8	2,122	2,122	2,481
HIV/AIDS	285,000	0.6	171,000	64,125	14,255
Progressive Non-Malignant Diseases					
Cardiovascular diseases (.67)	421,939	0.67	282,699	106,012	1,487
Cirrhosis of Liver	426	0.67	285	107	364
Congenital Anomalies	130,622	0.67	87,517	32,819	6,652
Endocrine, blood, & immune disorders	126,343	0.67	84,650	31,744	2,763
Meningitis	4,188	1	4,188	4,188	4,188
Kidney diseases	10,824	0.67	7,252	2,720	81
Protein Energy Malnutrition	7,032	1	7,032	7,032	7,032
Neurological conditions	570	1	570	570	570
Neonatal conditions	49,523	0.67	33,180	12,443	32,191
Tuberculosis (1.417% DR-TB)	221	1	221	221	221
TOTAL	1,039,341		680,717	264,102	72,285
Population Prevalence (All Ages)			1.76%	0.68%	
Rate/10K			309.42	120.05	
Average Daily Census				72,357	
% of Need Met				0.21%	

Table 7: Estimates of the Need for Children's Palliative Care in Zimbabwe

Diagnosis	**Prevalence 0-19**	**Symptom Adj. Factor**	**Estimated CPC Need**	**Specialised CPC Need**	**Mortality**
All Cancers	980	0.8	784	294	415
HIV/AIDS	236,000	0.6	141,600	53,100	14,075
Progressive Non-Malignant Diseases					
Cardiovascular diseases (.67)	147,529	0.67	98,844	37,067	235
Cirrhosis of Liver	427	0.67	286	107	24
Congenital Anomalies	37,673	0.67	25,241	9,465	1,019
Endocrine, blood, & immune disorders	24,930	0.67	16,703	6,264	228
Meningitis	212	0.67	142	53	228

Kidney diseases	4,764	0.67	3,192	1,197	55
Protein Energy Malnutrition	217	1	217	217	217
Neurological conditions	125	1	125	125	125
Neonatal conditions	37,072	0.67	24,838	9,314	7,868
Tuberculosis (1.417% DR-TB)	81	0.9	73	27	27
TOTAL	490,010		312,046	117,231	24,516
Population Prevalence (All Ages)			2.42%	0.91%	
Rate/10K			480.81	180.63	
Average Daily Census				32,118	
% of Need Met				4.64%	

4.2.2 Perception of the Need for Children's Palliative Care

The cross-section of respondents in this study, including the palliative care practitioners and stakeholders interviewed in the three countries, shared a common view of a very high need for palliative care for children. Respondents felt that HIV and AIDS, cancer and other life threatening and life limiting non-malignant conditions were the main contributors to the palliative care burden. The respondents attributed this to the large numbers of children living with HIV and those with malignancies. There was occasional mention of other conditions that were deemed as requiring CPC but cancer and HIV and AIDS were regarded as the major contributors to the palliative care burden.

Respondents, including health professionals in public and private institutions, palliative care practitioners and ministry officials across the three countries, made continued reference to children with cancer as well as those children living with HIV in justifying their perception of a high need for children's palliative care. In Zimbabwe, health workers also pointed to the existence of a significant group of young children born with HIV and living positively into teenage and adulthood, though they tend to be forgotten. These children were noted to be in need of emotional and psychosocial support in most cases. A significant majority were believed not to be on ART. Respondents generally opined that the children with malignancies have a lot of palliative care needs, particularly in terms of pain and symptom relief, as well as psychological issues.

> *"These children are there in the communities, and it's sad, they have a lot of issues but most people do not seem to recognise their need. They have issues besides the management of symptoms." PC Nurse, PC Organisation, Zimbabwe*

In Kenya, all paediatric cancers were reported to be contributing to the palliative care burden although some were noted to be more common than others and these include the blood tumours, lymphomas and leukaemia.

Interviewed palliative care workers also pointed to the existence of other conditions requiring palliative care. These respondents felt that a lot of children are in need of palliative care services due to, in addition to HIV and cancer, conditions that included cardiovascular diseases, congenital malformations, cerebral palsy and sickle cell anaemia. The latter was reported to be highly prevalent in the western districts of Kenya and the north-western districts of Zimbabwe (Mutoko and Mudzi districts). Cases of cerebral palsy, though restricted to some area, were reported by the in-country specialists to be on the rise in Zimbabwe. Some specialist doctors in South Africa also regarded children in emergency settings and suffering from trauma, largely arising from road traffic accidents and burn related injuries, as a significant sub-population requiring "emergency palliative care".

It was observed that across the interviews the perception of the need for palliative care was largely premised on end of life care and was therefore mainly based on the dying cancer and HIV and AIDS patients. This was also observed amongst the policy makers. Conditions such as cerebral palsy and sickle cell anaemia were not readily forwarded as contributing to the palliative care need. The respondents who readily noted conditions other than HIV and cancer were observed to be either health professionals with prior exposure to some form of CPC training background, hospice/palliative care workers or active advocates for palliative care and/or palliative care for children. Nearly all those interviewed from hospices and palliative care organisations did not present conditions other than HIV and cancer as contributing to their caseloads. Pain management, psychological/emotional support and cognitive development support were regarded as aspects of care essentially required by the children with the conditions mentioned.

Due to this view of palliative care as only end of life care, the perception that palliative care is no longer necessary for children with HIV, due to improved access to ART, was reported to be widespread amongst both service providers and the general public who seek the services. A ministry official in Zimbabwe however noted:

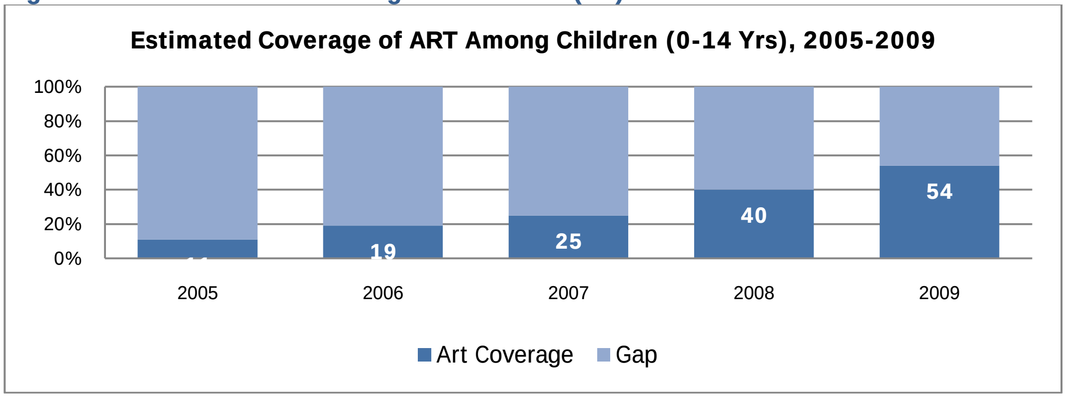
> *"…and there are also those with HIV. Yes there are ARVs but not all, especially children, are taking the medications and even if they are: they still have occasional pain problems…and also their wellbeing psychologically." MoH Official, Zimbabwe*

A palliative care doctor also remarked:

> *"Personally I have argued with professors in paediatrics who have said there is no need for palliative care in paediatrics because ARVs are there." PC Doctor in PC Organisation*

Despite recent improvements in ART coverage in the three countries, a significant number of the children living with HIV are not on ART. According to a UNICEF child rights and equity report[23], only 54% of children living with HIV were on ART in South Africa in 2009. The ART coverage amongst children aged 0-14 years in Kenya was estimated at 31% in 2011[24]. A 2012 briefing by the National AIDS Council (NAC) in Zimbabwe reported that according to the Ministry of Health and Child Care ART programme (2012-17) update report, Zimbabwe's estimated number of people in need of anti-retroviral treatment was 611,264 with 518,810 adults and 92,454 children. Only 43% of the children in need of ART are accessing treatment.

Figure 5: Paediatric ART Coverage: 2005-2009 (SA)



Data Source: South Africa's Children - A Review of Equity and Child Rights, South African Human Rights Commission/UNICEF

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[23] South Africa's Children - A Review of Equity and Child Rights, South African Human Rights Commission/UNICEF
[24] UNICEF 2011 Report, Countdown to Zero

"I think the ARVs have definitely changed the dynamic of palliative medicine that previously saw more children dying… that has changed." PC Doctor, Wits Palliative Care, SA

Despite the acknowledgement that universal ART coverage is still to be attained for children, more than half of the key informants expressed the opinion that the advent of ART certainly had an influence on the approach and way of providing palliative care. The effect pointed towards a strategic shift to focus more on adherence support, management of pain and opportunistic symptoms

Some palliative care practitioners felt there were mixed interpretations of the nature of palliative care and therefore the magnitude of the need has not been clear to many, including professionals. Almost all the interviewed health professionals pointed out that the community in general is unaware of the true nature of palliative care and therefore does not appreciate the need. This is discussed in later sections and is seen to influence the demand for palliative care service delivery. Discussions around this conclusively pointed to a mixed understanding of the definition of palliative care and perceptions of the actual need, with most people inclined towards regarding it as end of life care.

"Most people do not understand, like the gentleman I have just been talking to. He feels condemned that he has to come here, yet, what he has, I think why they brought him here, is because he needs to get his treatment urgently but he has been wondering if he should wait. So I think people do not get that idea they think when come here you are terminal, but we have been trying to change that." Doctor, Hospital Based PCU

Interviewed practitioners felt that whilst the definition for children's palliative care provides the general description of the approach the need exists for a more precise targeting framework which relates the intensity, duration and the package of care to the condition and stage of illness. One such example being the "emergency palliative care" needed for those children suffering from trauma and in a critical condition.

4.3 The Current Response

4.3.1 The Country Public Health Systems

The response to the health needs within the three countries is coordinated through specific line ministries or departments. In South Africa the Department of Health (DoH) oversees the national response whilst the Ministry of Health (MoH) in Kenya and the Ministry of Health and Child Care in Zimbabwe are the principal line ministries responsible for ensuring equitable access to health services for their respective citizens.

The health systems for the three countries make use of the primary care approach, which places emphasis on ensuring access to primary care services within the community. The health systems have specific levels of care, from the primary level to specialised referral centres at the national level. For South Africa and Zimbabwe the system recognises the primary, secondary (district), tertiary and quaternary levels of care. The Kenyan health system has six levels from Level One to Level Six.

In all cases, the referral system entails the referral of patients up to the district level when in need of secondary services, continuing upward if in need of specialised attention. Palliative care services were mainly noted at the tertiary level where specialised palliative care doctors, nurses or social workers provide support to specific hospital wards. In South Africa some provinces, such as the Western Cape, adopted an Intermediate Care Policy, which recognises an intermediary level between the primary and secondary/district levels. This level is envisaged to cater for step-down care from the district level. This level does not necessarily have public health facilities but may have private units that are recognised within the referral chain by the government facilities. An example is the Sarah Fox Hospital in Cape Town, which works closely with the government run Red Cross War Memorial Children's Hospital.

Since children in need of palliative care reside within the communities served by the public health institutions, it is anticipated that they receive the requisite care at the various levels. However, as shall be discussed in ensuing sections, there is very limited palliative care provision, let alone CPC, within the public health systems, particularly at the lower levels of care. This is due to a number of factors that include the absence of a palliative care policy framework and the lack of a recognised palliative care delivery model integrated within the system, inadequately trained personnel and other resources, particularly at the primary care level.

The palliative care response in the three countries has traditionally been provided by hospice and palliative care organisations which are predominantly Non Governmental Organisations (NGOs) registered as charity and welfare organisations. Strong networks of organisations in HIV and OVC programming have complemented the efforts of these organisations. The NGO hospices and palliative care organisations usually have a staff compliment comprising of nurses, social workers and in some cases doctors, who are trained in palliative care. These organisations provide services through in-patient units and/or community hospice service delivery models. Their package of services generally covers physical, psychosocial and spiritual aspects of care. The first children's hospice in South Africa was founded in 1996. It is important to note however, that very few of the organisations have such a specialised focus as to be regarded as a children's hospice.

Over the past years the Hospice and Palliative Care Association of South Africa (HPCA) has taken a leading role in the coordination of these palliative care services in South Africa. The HPCA together with the ICPCN, established in 2005, have been active in promoting CPC through education, information sharing, networking, advocacy as well as research and documentation. The Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) has led the coordination of the hospice and palliative care organisations within Zimbabwe. In Kenya the main actors in addressing the palliative care needs within the communities have traditionally been private organisations, mostly NGOs, who have been working at the community level under the guidance and leadership of the Kenyan Hospice and Palliative Care Association (KEHPCA). Currently 18 hospice and palliative care organisations registered with KEHPCA are providing palliative care for children. The national hospice and palliative care associations have been working closely with the line ministries in the three countries to integrate palliative care into their health systems and policies.

The study noted that in most cases the hospice and palliative care organisations do not have a child focus. In South Africa only 36 of the 178 organisations registered with HPCA were identified as providing services that include components of CPC. This lack of services to children, together with other factors that encompass the human resource and financial capacity of the organisations, extensively limit the scope and scale of the response to the need for CPC by these institutions. Whilst the exclusion of children in providing palliative care services was more peculiar to the South African context, organisations in Kenya and Zimbabwe, although inclusive of children, had limited numbers of children on their programmes or no specific child focused programmes.

The Community Health Worker (CHW) or Home Based Care (HBC) Caregiver is a vital component of the primary care approach. South Africa and Zimbabwe have a network of community caregivers who are attached to various service providers such as the palliative care organisations and hospices for service delivery and supervision. In Kenya, though present, some key informants in the public sector felt that the cadre was largely inactive due in part to the lack of direct support for their activities. In South Africa, the CHWs receive monthly stipends from the Department of Health and the Department of Social Development. According to HOSPAZ and ministry officials, trained Village Health Workers and HBC Caregivers in Zimbabwe receive monthly allowances of $14 and $15 respectively, which is disbursed quarterly through the Global Fund supported Community Systems' Strengthening programme. The CHWs have been pivotal in linking primary level facilities with the community through home visits and provision of prevention, care and support activities. The cadre's focus in the past years has been on patients and families living with and those affected by HIV and AIDS, including support for Orphans and Vulnerable Children (OVC).

Efforts to address the problem of orphans and other vulnerable children in Zimbabwe are coordinated by the Ministry of Labour and Social Services (MoLSS) through the Department of Social Services (DSS). The country is currently implementing the 2nd phase of the National Action Plan (NAP II) for OVC, the overall purpose of which is to enhance all vulnerable children's access to effective child protection services, including social welfare and child friendly justice services, through the delivery of innovative community based services nationally. The programme's strategy is anchored on the implementation of Child Protection Committees at community, district, provincial and national level.

4.3.2 Reach and Coverage of Response

The study noted minimal palliative care service provision, including for children, within the public sector of the three countries. In addition, in all three countries, service provision by the palliative care and hospice organisations is mainly localised, with minimal reach.

In **South Africa**, service provision in the public sector is mainly localised within the institutions supported by a few palliative care specialists. If we are to consider the average number of children seen at such public hospitals with a team providing palliative care to be 799[25] per hospital per year and also assume that each of South Africa's nine provinces has one hospital providing palliative care to children we can estimate the reach through public health facilities to be 7,191.

The operations and reach of hospices and palliative care organisations is also localised. Only 36 organisations were identified as providing these services in this exercise. All 20 of the organisations that returned the APCA Self Assessment Tool reported attending to a total of 4,061 children in the 2012 operating period. This could be extrapolated to give an estimated total of 7,310 children. The HPCA HDMS database, however, indicates that on average the hospice and palliative care organisations attend to 5,791 children patients and provided at least one intervention to 5,508 OVC monthly. A total of 7,273 OVC were on register in December 2012 alone.

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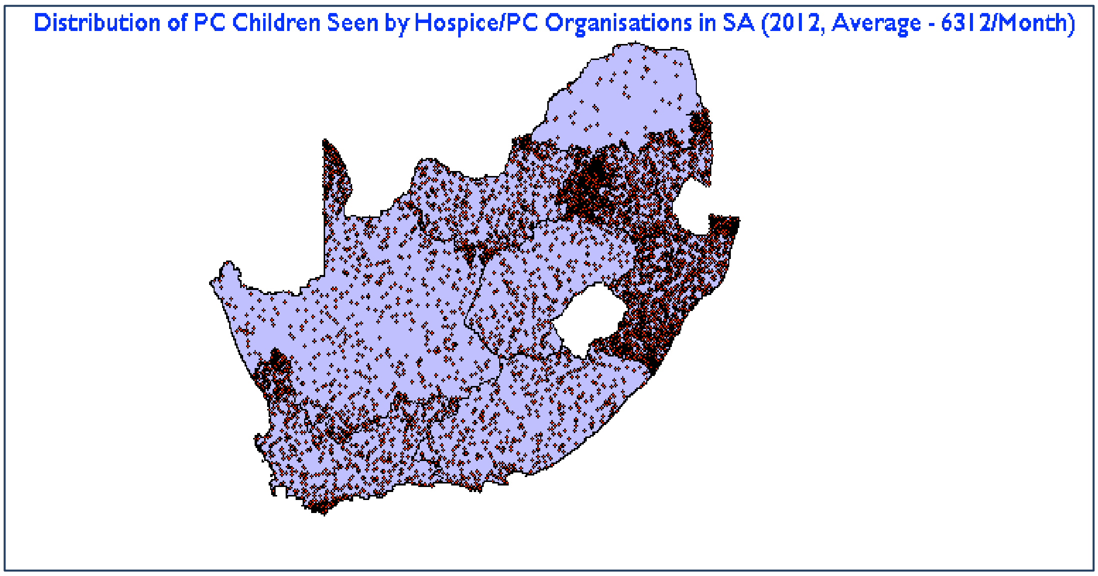
[25] Based on Capacity Self-Assessment Survey (Wits and Dora Ngiza Hospital)

Figure 6: Spatial Distribution of CPC Clients - South Africa



Source of Data: HPCA Database

If we are to consider the annual estimated number of children reached in the public facilities and those reached by the hospices it would imply that **a total of 14,501 South African children were reached in 2012. This represents only 1.8% and 4.8% of the need** based on the estimated need for annual generalised palliative care and specialised palliative care respectively.

In **Kenya** in the past year, the Ministry of Health, with support from KEHPCA, has embarked on strengthening the integration of palliative care into the health system. KEHPCA, through its partnership with The Diana, Princess of Wales Memorial Fund and True Colours Trust under the Waterloo Coalition[26] is providing technical and funding support to the Ministry for the establishment of Palliative Care Units (PCUs) at Level 4 and 5 hospitals in the country. The project is specifically targeting the establishment of 11 PCUs, which are anticipated to benefit 4,000 new adult cancer patients, 5,000 adult people living with HIV and AIDS (PLWHIV), 500 new paediatric cancer patients and 1,000 children living with HIV receiving quality holistic care from within the units per year. 5 of the targeted 11 units were operational at the time of data collection for this study. These units were set up to further the training of doctors, nurses and palliative care practitioners in CPC during the 2nd half of 2012. The strategy in the medium term is to have the established PCU's at the hospitals working in partnership with hospices in their catchment areas to provide support and mentorship to 30 lower level hospitals.

If one is to assume that the 5 operational sites are proportionally meeting the targets set for the 11 sites, we could estimate the total number of children in need of palliative care and who received care from a trained professional at these sites in a year, to be 682. However, this would be an overstated estimate when using the 2012 reference year since they had not been fully operational then. For instance, one of the hospitals that strengthened its palliative care services for children is Homa Bay District Hospital. This unit was established after the hospital paediatrician received training in CPC facilitated by ICPCN and KEHPCA. Homa Bay Hospital attended to only 15 children in the 2012 period. A number of reasons were noted as the main barriers to the provision of palliative care for children at this hospital. These included the lack of awareness amongst staff, patients and community of the available services; the lack of adequately trained staff (only one paediatrician) and the absence of a central coordinating place for palliative care within the facility. **The total number of children that received**

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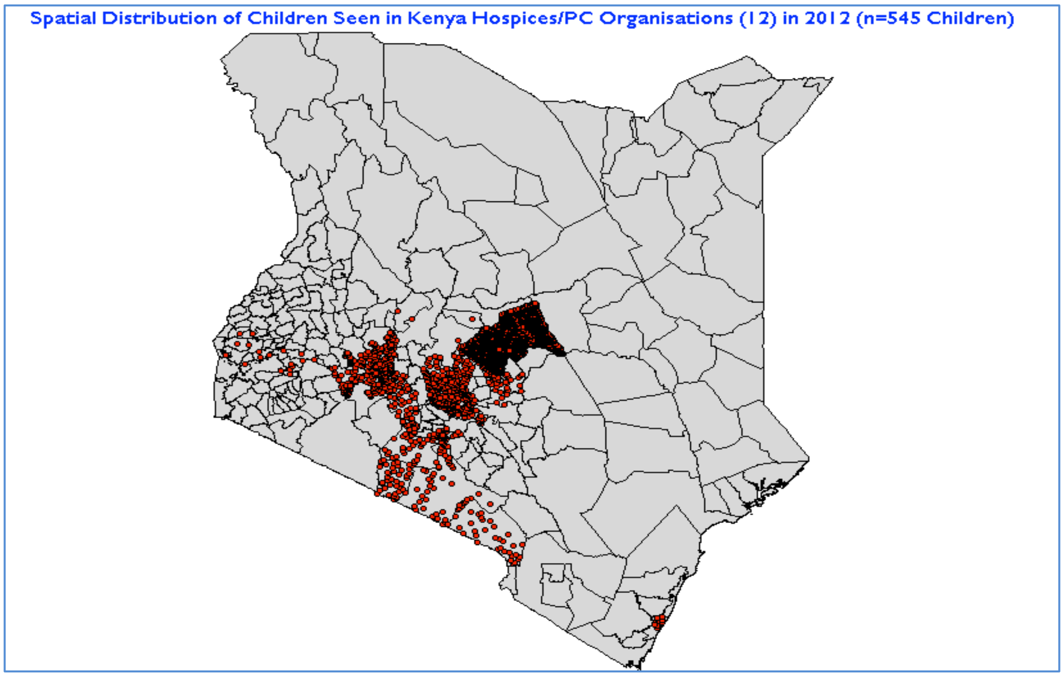
[26] Collaboration of Donors and PC Organisations working in Kenya and Malawi

palliative care services from hospice and palliative care organisations in Kenya in 2012 was 545 or less than 1% of the need for specialised services.

Figure 7: Spatial Distribution of CPC Clients - Kenya



Source of Data: KEHPCA Database

As can be seen from the map the provision of palliative care, particularly for children, is localised and covers only a few districts of the country. This justifies the call for the integration of palliative care services into the health system in order to improve coverage.

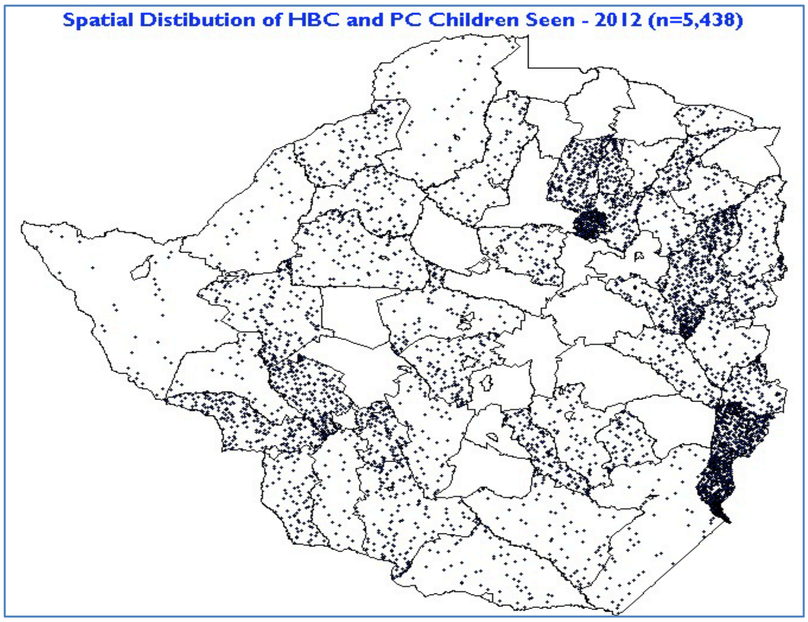
> *"…these [Hospice and PC Units] have mainly been centred around the country and that has been a challenge. So now we had a meeting with the Ministry of Health and we decided we needed to go to other parts of the country where there is nothing." KEHPCA Official*

The number of children in Kenya seen by the palliative care organisations and those estimated to have been seen in the public health facilities combined is 1,257 which represents less than 1% of either the generalised need or specialised need. This therefore implies that the current reach is at most 1% of the actual need for CPC.

Zimbabwe has in the past years witnessed some progress in the provision of palliative care in the public sector. However, despite numerous in-service trainings of health professionals that were conducted through the Ministry's partnership with HOSPAZ, Island Hospice Service and other partners and signify some positive steps towards palliative care integration, there is currently no specific palliative care service delivery model within the system. There are no palliative care funded posts either at policy or implementation level. However, there are some isolated cases of established palliative care teams that have been developed by trained palliative care practitioners. At Parirenyatwa Hospital, one of the main referral hospitals in Harare (Central Level), a team of paediatricians with a background in palliative care have championed the multi-disciplinary team approach and have also incorporated palliative care into grand rounds and teaching. Mutare Provincial Hospital (Tertiary Level) also has some trained professionals who have ensured palliative care provision is recognised within the facility, allowing for intra-facility referrals. Mutambara, Morgenster and Karanda Mission Hospitals have also been recognised by HOSPAZ as providing some structured service delivery in palliative care. Generally the public facilities do not have a cross-cutting model for palliative care delivery but the numbers of professionals in the health sector that have received some training in palliative care indicate that some children would have contact with these professionals.

In the absence of explicit indicators on utilisation of palliative care services in the Health Management Information System (HMIS), it is difficult to estimate the number of children requiring palliative care in public facilities. However, in view of the complementary nature of the service provision by the NGOs and Mission Facilities, the number of children seen through these organisations can provide a fair estimate of reach at the national level, with minimal risk of double counting. Based on the Global Fund supported Community Systems Strengthening programme as well as privately funded initiatives, a total of **5,438 children were seen through Hospices/ Palliative Care Organisations or PCUs in some public facilities with the support of CHWs. This represents 4.64% of the estimated need for specialised palliative care**. However, it should be noted that the majority of the Global Fund supported organisations were implementing Home Based Care programmes in specific districts and these were aligned to addressing HIV and AIDS.

Figure 8: Spatial Distribution of CPC Clients - Zimbabwe



Data Source: HOSPAZ Database

Through the efforts of HOSPAZ and other stakeholders, palliative care was integrated in the CHBC programme, mainly through training guided by a revamped Harmonised Training Module that had Palliative Care as one of the nine modules. In addition, CHBC organisations, and other organisations such as KIDZCAN, Island Hospice Harare, Island Hospice Bulawayo and the Children's Rehabilitation Centre also provided care and support to children with Cancers and other malignancies. The map shows the geographical distribution of the children seen during the year 2012.

The table below provides a summary of the share of the estimated need for specialised palliative care for South Africa, Kenya and Zimbabwe.

Table 8: Estimates of Children Reached through Public Facilities and NGO Hospices

Country	No. of Children Reached	% of Est. Specialised Need
South Africa	14,501	4.76%
Kenya	1,257	<1%
Zimbabwe	5,438	4.64%

4.4 Gaps in Service Provision

The comparative analysis of the estimated need and the current reach shows a significant gap in the response. These gaps were analysed from a capacity perspective and by looking at specific domains relating to the capacity at institutional and system level. Particular focus was placed on the Policy and Strategic Framework, Service Delivery, Human Resources (Numerical Adequacy and Education), Pharmaceuticals and Financing of the palliative care services.

4.4.1 Policy and Strategic Framework

The availability of a national policy and strategic framework that recognises the importance of palliative care and includes strategic actions as well as possible sources of financing is fundamental to addressing an identified development need.

The three countries exhibited varying levels of progress regarding policies and strategies for palliative care in general and specifically for children. There are currently no stand-alone palliative care policies in each of the three countries although KEHPCA and HOSPAZ have been working closely with their line Ministries in Kenya and Zimbabwe respectively to develop this document. In particular, the Ministry of Health and Child Care in Zimbabwe is near finalisation of a free standing National Palliative Care Policy. When endorsed, Zimbabwe becomes one of the very few African countries with a palliative care policy in place.

> *"…we have come a long way, consulted far and wide. But as we speak it has now been forwarded for endorsement at the top management level." HOSPAZ Official*

Both the HOSPAZ and Ministry officials interviewed expressed their excitement about this achievement and indicated that this policy contains specific sections on palliative care for children.

The key persons interviewed in South Africa felt that these issues are not adequately covered and not prioritised. They felt that there was "lip service" when it comes to palliative care at the policy making level. As in most cases, there seemed to be consensus on the need for palliative care amongst all stakeholders but it never seems to be prioritised in strategies and key action points. It was noted that palliative care does not appear in the plans of both the DoH and Department of Social Development. This was mainly attributed to the prioritisation of the MDG areas that have not performed well and which includes primary care for children. A great deal of effort has, however, been made to ensure that palliative care and CPC in particular is included in key health strategy documents in all the three countries.

The South Africa National Strategic Plan on HIV, STIs and TB has one section with specific reference to palliative care. Strategic Objective 3 on Sustaining Health and Wellness and specifically sub-section 3.2 (Ensuring that people living with HIV, STIs and TB remain within the healthcare system, are adherent to treatment and maintain optimal health and wellness) indicates the deliberate efforts to integrate palliative care in the referral system and the acknowledgement that facilitating referrals for special needs, including palliative care, would strengthen PHC. However, there does not seem to be any additional references or strategic actions emphasising the role of palliative care or CPC.

> "The PHC system should be re-engineered to facilitate the following:
>
> - ✓ Active screening for medication side-effects, with appropriate referral for side-effects or specific needs, including palliative care" SANASP 2012-2016

The MoH and KEHPCA officials frequently made reference to the Kenya National Cancer Control (NCC) Strategy (2011-2016) and the Cancer Treatment Guidelines as documents where key stakeholders had ensured the inclusion of palliative care.

The Cancer Treatment Guidelines, though not yet finalised, were noted to have incorporated key sections on palliative care and specifically on palliative care for children.

> *"…We insisted that we must have a section on paediatric palliative care, pain management for example because it is different from adult pain management in some ways so we even put that part. Now the ministry is thinking of doing a protocol, which is more comprehensive. So we looked at putting palliative care into the document on non-communicable diseases (NCDS), we have also included palliative care for children and also for HIV and AIDS." KEHPCA*

MoHCC in Zimbabwe is set to launch the National Cancer Prevention and Control Strategy, which has integrated a component on palliative care and is also widely seen to assist in shaping the management of cancer and other Non Communicable Diseases (NCDs). The other policy and strategy documents that were mentioned during the interviews include the National Health Strategy, Non-Communicable Disease Control Policy and National Standards for Palliative Care as key guiding documents.

With the exception of the palliative care policy that is still in draft and is to be adopted, the other documents either place palliative care in the context of cancer care and/or looking at terminal illness. The National Health Strategy has only three reference points for palliative care and in all of these the focus is on the provision of care to cancer patients who are terminally ill.

Discussions with some palliative care organisations and some Ministry officials in Zimbabwe suggested that having the imminently expected policy in place may present a more holistic way of addressing the problem. Commenting on the possible next steps, a palliative care doctor noted:

> *"I may not know the next steps but my wish is if we could start now having that support of the policy document and building palliative care teams in every hospital, even if it starts at central hospitals. I think this is what is lacking and so far it has been like NGO driven, but with the policy it can facilitate integration and availability of medicines." Doctor - PC Organisation*

4.4.2 Palliative Care Service Delivery

a. Package of Care

The uniqueness of palliative care is, to a large extent, anchored on the holistic nature of care provision, which places emphasis on comprehensive assessment and addresses physical, emotional, social and spiritual needs. In addition, the family is acknowledged as the unit of care and therefore involvement of the family in care planning, management and even bereavement support where necessary, is critical.

Most respondents felt that the current response to the need for CPC is limited in both coverage and the comprehensiveness of the package of care. Public health facilities in all three countries were reported to be providing essential preventive and curative services at various levels. However, these are mainly focused on disease specific treatment and clinical care aspects, for example, ART, management of OI infections and other physical symptoms, nursing of wounds and nutritional support. Despite some variances in capacity to provide primary care services across facilities and countries, a commonly referenced gap in service provision was that of pain management.

Inadequacies in pain management were often pointed out to be in existence at the different levels, particularly at the primary level. Challenges in pain management were attributed to a combination of factors centred primarily on the health worker. These factors were noted to fall broadly in the thematic areas of knowledge and attitudes. Respondents highlighted that the majority of personnel in the public sector have not been exposed to palliative care or CPC training and therefore lack the requisite knowledge and skills to undertake case identification, the impeccable assessment of pain and prescribing of the required medications. Respondents noted the latter to be very common in relation to morphine.

Another commonly identified gap was the minimal psychosocial support provided by health professionals. Of note, counselling to address the emotional issues associated with an illness; communication on diagnosis, prognosis or the illness in general; children and family involvement in planning and decision making; breaking bad news and bereavement counselling were commonly reported across the countries as significantly lacking. This was mainly attributed to the lack of skill amongst the service providers and the general shortage of staff. In most instances, the nurses and doctors were noted to lack the necessary time to provide comprehensive psychosocial support to children due to their heavy workloads.

In Kenya, nearly all respondents felt that there was minimal counselling of patients and families in the public facilities, apart from the recently established PCUs. Health professionals generally felt that this was partly due to the lack of requisite skills in counselling and communication. This deficit was attributed to a limited knowledge of palliative care and the absence of training in discussing difficult issues with the child and family.

"...However this counselling is very good for the paediatric oncology ward, the thirty patients who are there - the parents come every Thursday and meet with one of us and we tell them what is happening with their child. But for the other wards there is very little counselling that goes on." Paediatric Oncologist, Kenya

The PCUs in the Kenya hospitals noted that they provide pain management, counselling and symptom management but that they are still in the process of setting proper mechanisms for bereavement follow-up and counselling.

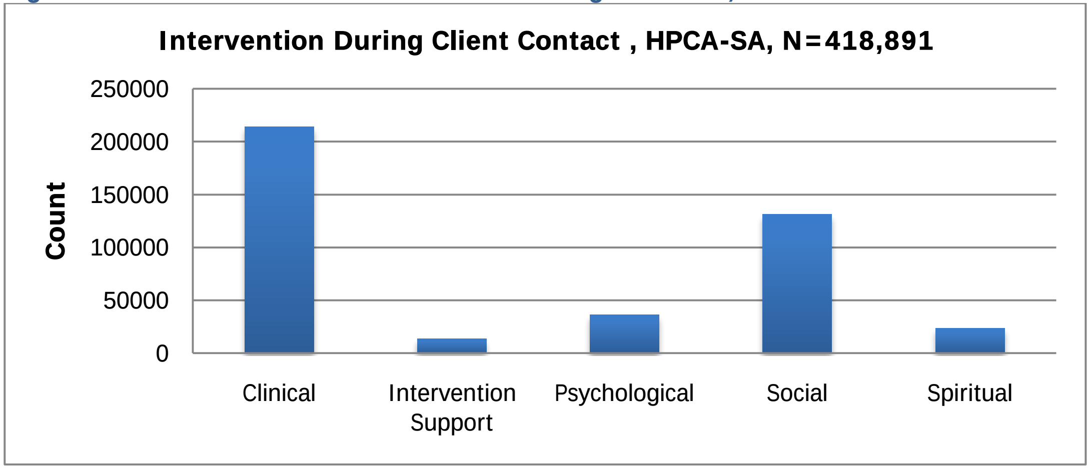
Other professionals pointed to the lack of adequate space (such as a room) and time to provide comprehensive counselling to the clients in the public health setting. They felt that personnel manning the facilities are in most cases overwhelmed by patients and usually do not have adequate time for counselling. In addition, some facilities and/or wards do not have the privacy to provide counselling.

"...I think the main problem is care of children with chronic illnesses has not been a priority, so there are too many patients in a ward and that is something that has come out." PCU Paediatrician

The hospice and palliative care organisations in all three countries report the provision of a more comprehensive package of services for CPC. However, responses reflect that these organisations are skewed more towards the child's physical and clinical care at the expense of emotional, social, spiritual and bereavement support. Interviewees in Kenya and Zimbabwe stated that the services of the palliative care organisations were comprehensive. Gaps in bereavement support were, however, noted across most institutions. Those interviewed mentioned the management of pain and other symptoms as areas needing development.

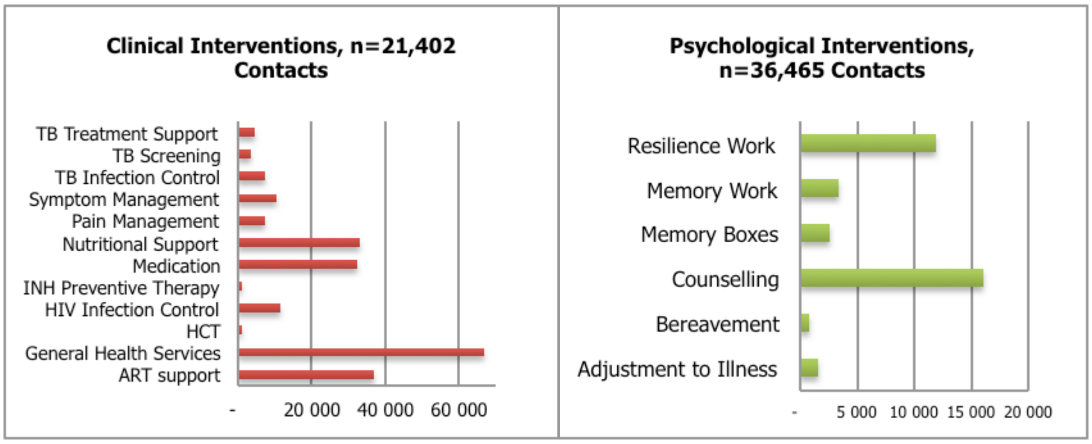
Analysis of data from the HPCA Database indicated that of the 418,891 successful contacts made with child clients in 2012, slightly more than half (51%) included provision of a clinical intervention. Social and psychological interventions were provided in 31% and 9% of the contacts respectively. Spiritual support is reported very low amongst the contact interventions.

Figure 9: Client Contact Interventions - HPCA Organisations, 2012



The clinical interventions were mainly in the form of general health services, medication, nutritional support and HIV infection control. Psychological interventions comprised of counselling, resilience and memory work with children.

Figure 10: Types of Clinical and Psychological Interventions for Children under HPCA, South Africa

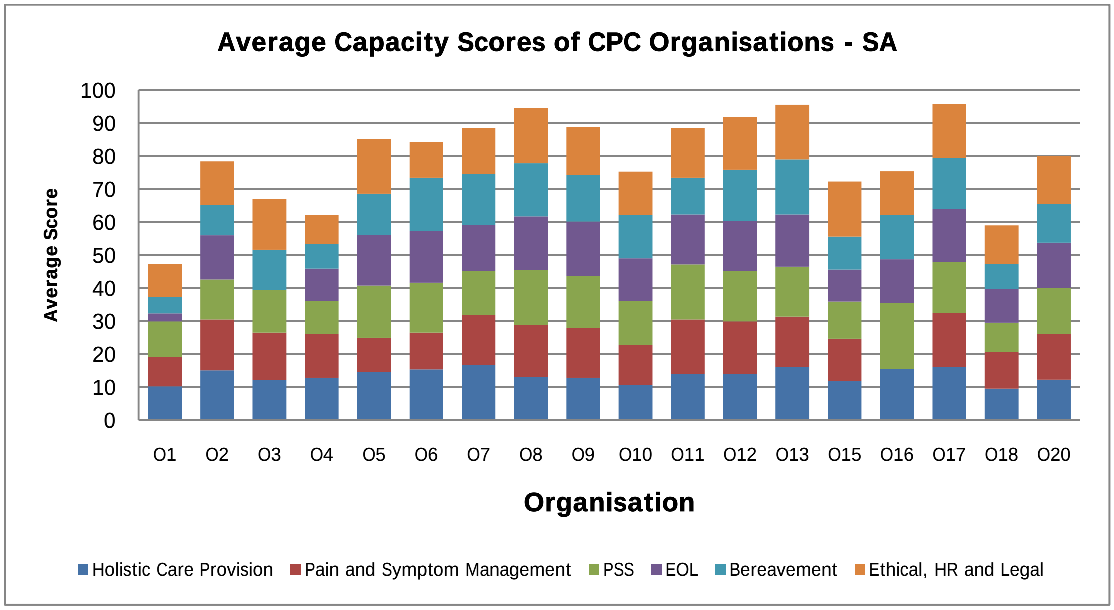


b. Organisational Capacity

The capacity assessments provided indications of major challenges in aspects relating to pain management, communication with children, and having to deal with the dynamics of the children's needs in general.

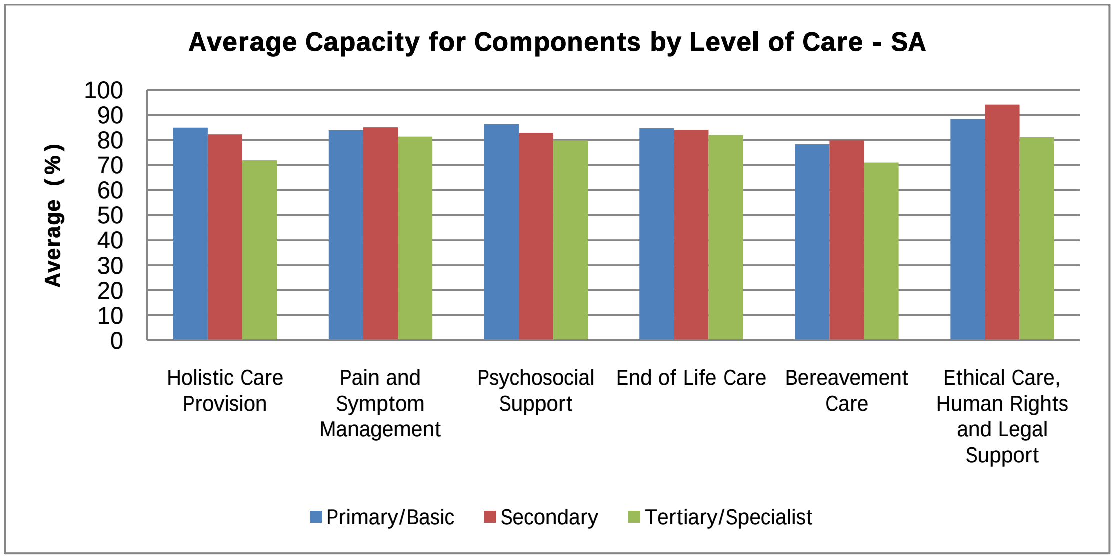
The chart below indicates that 19 of the 20 South African palliative care organisations that participated in the capacity assessment component of the study reported providing the six critical components of palliative care for children under review: holistic care provision, pain and symptom management, psychosocial support, end of life care, bereavement support as well as addressing ethical, human rights and legal aspects of care. The average capacity assessment scores for the majority of the organisations (15 or 75%) ranged between 60% and 90%, and the overall mean was 75%. The capacity scores were obtained through computing the total attained score aggregated from the Likert Scale marks for each indicator and divided by the total possible marks that would be attained.

Figure 11: Capacity Scores for CPC Organisations in South Africa



The contributions of the components to the organisation's averages were consistent across the organisations/institutions. The averages attained for each of the six components also exhibit minimal differences across the levels of care as shown by Figure 13 below.

Figure 12: Capacity at Different Levels of Care for Organisations in South Africa



The above indicates organisations are generally providing moderate to high standards of care based on their self-reporting. Nevertheless, further analysis of the indicators constituting the domains of care affirms the perceptions that to some extent there are still gaps in caring for the children, especially on issues of communication, death awareness and preparation as well as pain management. Figure 14 below shows that key indicators relating to pain and symptom management at the primary level were largely "often" or "always" met. However, the proportions of organisations reporting an absence or infrequent occurrences increased for the indicators relating to the provision of pharmacological and/or non-pharmacological aspects of pain and symptom management; access to Step 1 to 3 analgesics and the availability of clear instructions for pain and symptom management.

Figure 13: Pain and Symptom Management Scores

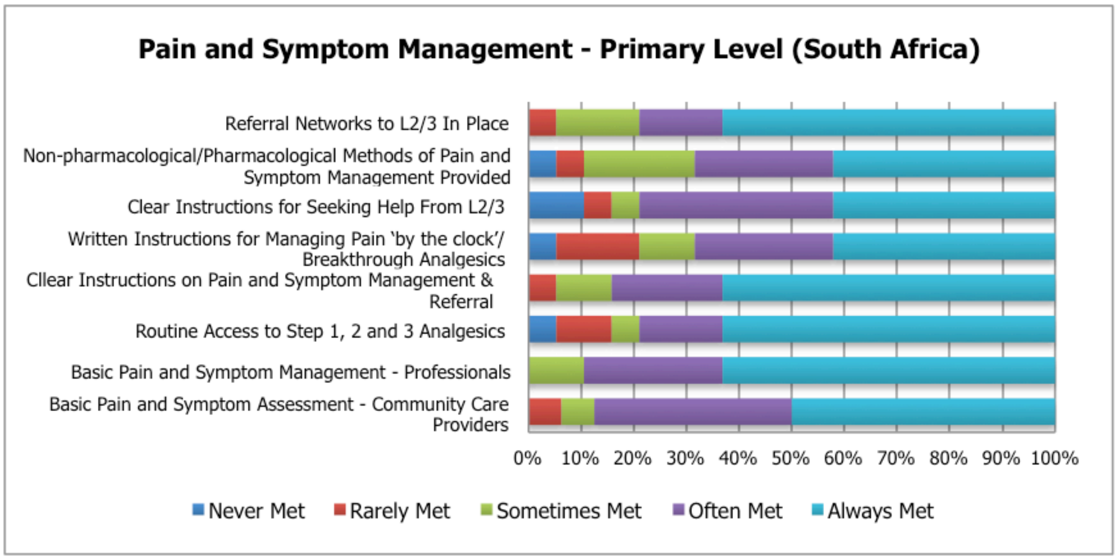
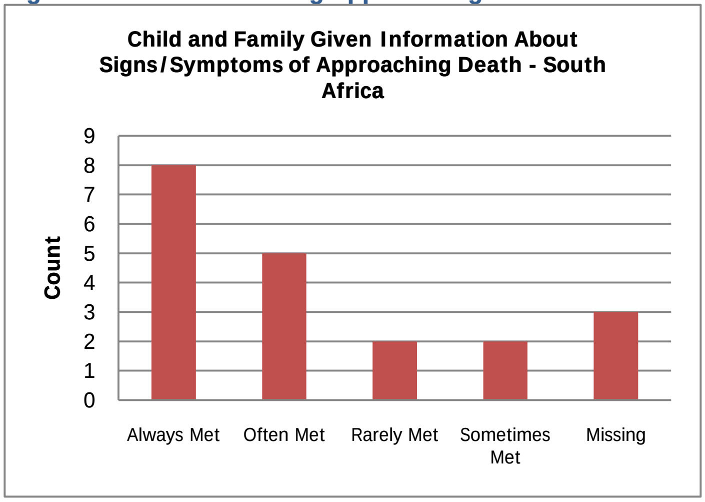


Figure 14: Communicating Approaching Death



Some of the institutions currently providing care and support to children reported doing so by “default” as they attended to the children of their adult clients. As such, they mainly apply the basic aspects of palliative care in caring for the children but without in-depth understanding and skill to deal with the differing needs of children. It is in this regard that respondents commonly felt that these organisations “fear” or are “nervous” to deal with children. The emotions that normally come with caring for an ill or dying child were also seen to contribute immensely to this fear. As a result, the majority of hospices in South Africa exclusively attend to adult palliative care patients.

> *“People are quite scared of paediatrics, especially the children’s palliative care. Even the nurses at our unit, we have said to them they could come in and help and they say [ooh] it is too heart breaking. It is always feared, it is always more emotive the child dying than an adult so that is also our bigger problem.” PC Specialised/Practitioner*

The CPC component provided by the majority of those that offer CPC in South Africa is due to their inclusion of children in the beneficiary targeting. There are some exceptions amongst the hospices. For instance, Drakenstein Hospice smoothly transitioned to provide CPC services after receiving CPC training.

It is significant to note that the hospices and palliative care organisations predominantly provide end of life care since the majority of clients are referred late when they are no longer responsive to any curative treatment. Most patients therefore endure long periods of suffering without adequate pain control, prior to referral.

Discussions with family on issues related to death and dying, particularly preparation for death, regularly present challenges to the palliative care practitioners. Respondents felt this was largely due to cultural beliefs and how society views the subject matter. One palliative care practitioner noted the following when responding to the question on how they deal with death and dying issues:

> *"We usually involve the spiritual leaders but actually we have been finding it to be very difficult here in Kenya because talking about death is a taboo so they are not so keen to listen but you bring it as a way of counselling but we have to tell them the prognosis." PC Nurse*

In all three countries less than half of the organisations reported consistently providing the children and their families with information about the signs and symptoms of approaching death. Only 5 reported doing so often. Mechanisms for follow-up bereavement support were in place although these were noted to vary in terms of the approach and frequency from organisation to organisation. Commonly follow-up is undertaken 2-4 weeks after death and bereavement counselling is provided to the family and children. Some hospices involve the local clergy in these follow-up visits.

Figure 15: Capacity Scores for CPC Organisations - Kenya

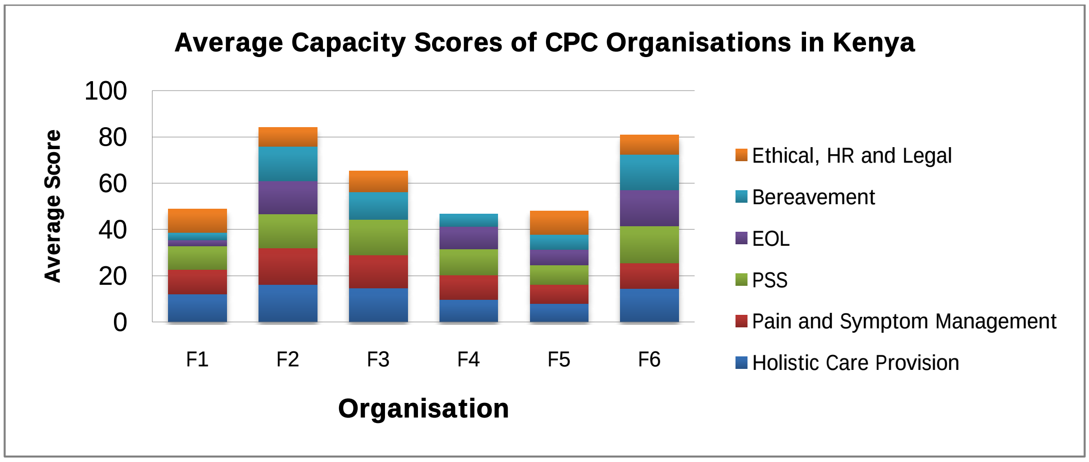
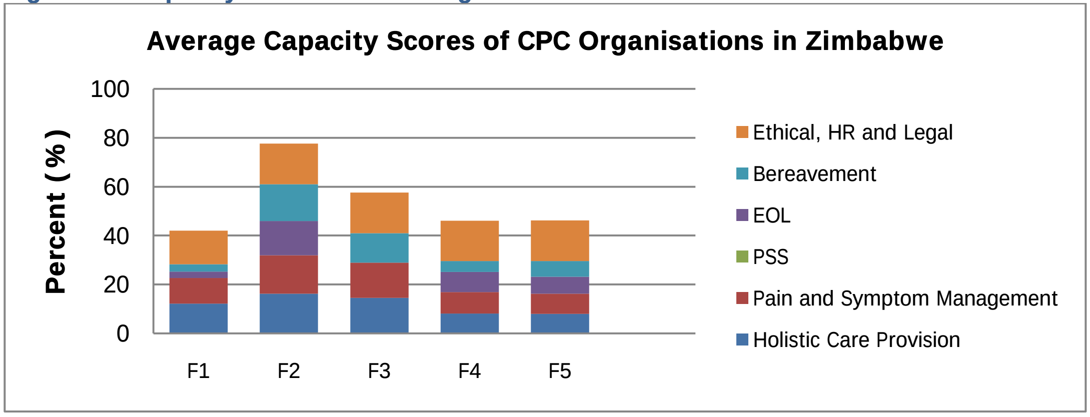
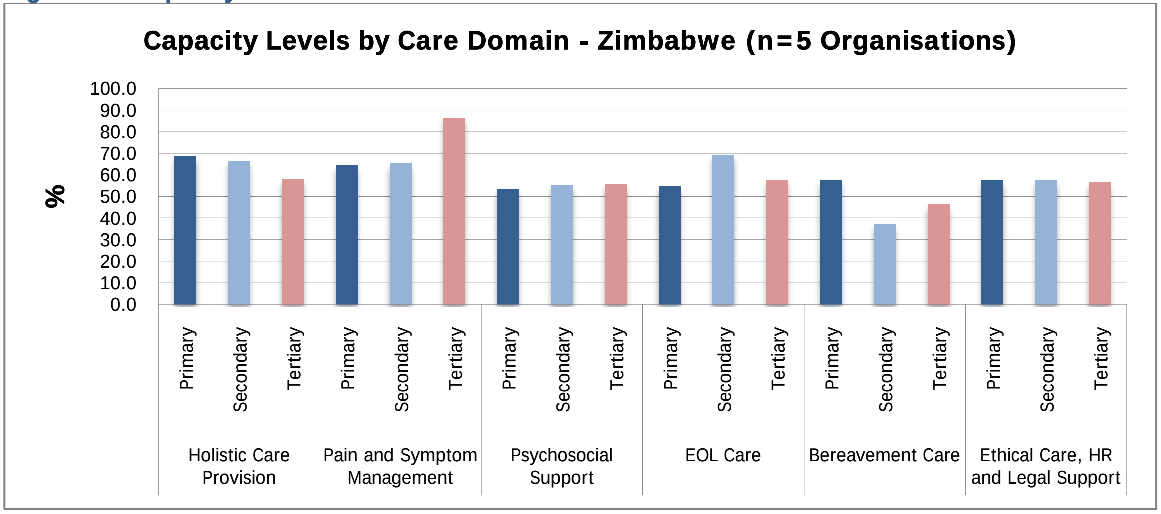


Figure 16: Capacity Scores for CPC Organisations - Zimbabwe



In Zimbabwe, specialised care is provided through a few organisations. It is within these institutions, such as Island Hospice Service Harare, Island Hospice Service Bulawayo, Mashambanzou Care Trust and Seke Rural Hospice that the cross-section of the key components of palliative care are reflected to some extent. Spiritual counselling, although a component integrated with the care, was seen as an area requiring further strengthening. The other hospices and palliative care organisations tend to focus on clinical and emotional support, although pain management strategies are not clear and, in most cases, tend to have limited attention. Island Hospice Service (Harare and Bulawayo) undertake detailed pain management and provide morphine to their clients. Within other organisations however, internal strategy documents or care guidelines simply highlight that for pain management they would “liaise” or “network” with organisations such as Island Hospice without providing clear, documented referral systems for when this support is required. The clear danger of this system is that pain is not adequately addressed amongst their clients. The intention to collaborate with the specialised organisations is commendable; however this should be supported with clear structures and systems.

Figure 17: Capacity Levels and Domains of Care - Zimbabwe



Significant gaps still exist in the capacity of HBC organisations to identify pain in patients, conduct comprehensive assessments and manage pain. The management of other symptoms, ART adherence support and counselling have been observed to be good amongst these organisations. According to most respondents, death awareness and preparedness continues to be a challenge, particularly when dealing with children. The topic was the second least frequently discussed by health professionals with clients, according to the situational analysis, following on from “funeral planning”. In most cases bereavement support is not systematic but tends to be limited to funeral attendance and follow-up discussions. It was evident that Island Hospice is at another level in the provision of bereavement support, as their follow-up periods and sessions are structured and they have a specific programme for bereaved children which runs for 8 consecutive sessions and includes the guardians.

It was noted that those providing specialised care were in most cases dealing with the critically ill and the dying. These were reported to be referrals for specialised care.

An important aspect to note regarding the care provided by the hospice and palliative care organisations is that their targeting is inclined towards clients requiring end of life care and most of the cases are predominantly children with cancer and HIV.

c. Referral System

The referral systems for CPC builds on the public health system’s referral chain which recognises the different levels of care as well as the hospices and other palliative care units (including step-down care in South Africa). Organisations reported having written guidelines on managing pain and symptoms and knowing when to refer to higher levels. The study noted that in all of the three countries, referrals to higher-level service providers are probably the most efficient. Participating organisations acknowledged the existence of referral systems for pain and symptom management as well as for psychosocial support services.

Referrals within the public health system is clearly documented and is based on the levels of care, with each case requiring a higher or more specialised care being referred upwards from the primary level. This therefore also applies to children presenting with specific conditions requiring palliative care. With the introduction of PCUs in Kenya, patients are now referred within the hospital to the specific units. However, it was noted that the wards that mainly refer to the PCU or are currently working with the units are the oncology wards. Referral from other wards for other conditions that may be life threatening or life limiting is still low and this was noted to be as a result of poor awareness levels. The downward referral was observed to be limited and a barrier to effective continuity of care.

"It is the other way around which does not seem to be working too well. We receive very few paediatric palliative care referrals from higher-level service providers." HPCA

In addition to the limited downward referrals to the hospice and palliative care organisations, the lack of feedback on the upward referrals was also reported as a cause for concern.

Palliative care practitioners at the PCUs in Kenya felt that health professionals at the lower level continue to refer clients back to the hospital for further curative efforts such as chemotherapy or radiotherapy despite previous efforts and clear discharge plans.

"…say if you are from Malindi, do you know where that is? It is pretty far so we get them calling us because the doctor there is suggesting that they come back but we would have given chemotherapy, radiography and they can manage the patient there. … and sometimes I have to tell the patient to educate the health worker … "tell him you are on morphine, tell him to keep giving you morphine, tell him to admit you for blood transfusion." Paediatrician PCU, Kenya

There does not seem to be a documented referral system that links the public facilities to the hospices although there is a general awareness of the services and location of the hospices and the need to refer. The Hospices in Kenya are recognised service providers and in most cases are located within the premises of the government owned hospitals; hence referral to these institutions is recognised within the system. The hospices reported referring their clients to the public facilities for specialised diagnostics/investigative procedures as well as treatment such as chemotherapy and radiotherapy. However, the hospices felt there were gaps in the referral from the public facilities. In addition, there is very little evidence to suggest a continuum of care at the community level after discharge. There is some mention of community health workers but these seem to be either inactive or limited to some slum areas and their operations do not appear to be widespread. The CHWs have not received training for palliative care for children and are also not on any payroll, incentive or stipend mechanism.

"The community health workers are there but they are not working because they are not paid, they are expected to volunteer, they usually try and they were forming a group where a community health worker takes care of twenty households but they got discouraged because there are no incentives at all. When they started they were not tackling palliative care but they were for maternal and newborns so those are the main things. When you look at the training curriculums most of them are based on maternal and newborn care…" PC Paediatrician, District Hospital

Challenges in referrals mainly result from the attitudes of health workers in the public facilities and their willingness to refer. All the hospices interviewed highlighted that very few children were being referred from the main facilities. The respondents felt that this was as a result of health workers at the facilities wanting to continue trying different curative options before referring to the hospice. The health workers, particularly the consultants or specialists, were seen to regard referral to palliative care as a sign of giving up or failure. As a result referrals are made late when the condition has progressed. This attitude was regarded to be associated with a lack of adequate palliative care knowledge and understanding by the professionals and their regard for it as only end of life care. Another important aspect raised by one health professional was that there seems to be inadequate knowledge by professionals of the care and package of service at the hospices as well as their capacity. Therefore some professionals in the heath sector may not value early referrals to these institutions. The discussion noted the need to build confidence in the utilisation of referral systems through facilitating greater awareness of available services and the capacity of service providers by all actors in the referral chain.

d. Barriers to Coverage/Reach

As previously highlighted, a total of 21,196 children received palliative care services from either a hospice/palliative care organisation or through contact with a trained health worker in a public facility in the three countries. This represents at most 4.76%, <1% and 4.64% of the estimated specialised need for South Africa, Kenya and Zimbabwe respectively. The provision of services was observed to be mainly localised around the service providers. In their responses, the interviewed service providers attributed the low levels of reach to a number of reasons, outlined below:

- **Referrals** Hospice/palliative care organisations and PCUs reported receiving few referrals of children and this, as discussed in the previous section, was seen to arise from a lack of knowledge of palliative care and some negative attitudes of health workers towards the services.

- **Inclusion Criteria** Nearly all interviewees pointed to the need for a widely understood inclusion criteria for palliative care services; one that can attempt to answer the frequently asked questions such as: Which diseases/conditions should one consider? At what stage do we start? Are there different levels of palliative care and when do they apply? Respondents felt that there were varied interpretations of the current definition and that most professionals generally regarded it as end of life care mainly for cancer and in some cases for HIV/AIDS. The lack of a clear inclusion criteria inhibited comprehensive case identification, referral and management. This was highlighted as one of the reasons why the enrolment in most institutions providing CPC is comprised predominantly of cancer patients and those with HIV/AIDS. The two disease categories combined represent only 15% of the estimated CPC need, using either the general or specialised need. The question that normally presents is, “Who is targeting the remaining 85% need?”

- **Lack of Demand Creation Initiatives** The lack of awareness and understanding of palliative care was reported to go beyond the health professionals, to the community. Respondents noted that one of the reasons there are very few children using the service is that the community is not aware of the service and how it can help them. Strongly related to this point is the influence of contextual factors, such as culture and religion, on the uptake of services. An example provided being where a wife may be sent back to her home due to the illness of the child or her own illness.

> *“…Then the community here is very superstitious so anything that happens to a child they say somebody’s hand is behind that even when you tell them that it is cancer so they take the patient to a witch doctor .” Palliative Care Nurse, Coast Hospice*

- **Organisational Capacity** The capacity of service providers to absorb the demand for their services is critical. As discussed in earlier sections and in some to come, there are challenges relating to the numerical adequacy of skilled palliative care personnel and in funding for service delivery. Although none of the service providers suggested that they have been overwhelmed by the need for their services, aspects of capacity need to be considered if the other factors highlighted above are addressed.

4.4.3 Human Resources and Palliative Care Education

The human resource capacity in terms of both the availability of staff and their children's palliative care knowledge and skills were of critical importance. For this reason current efforts in children's palliative care education were also explored. The numerical inadequacy of health workers is noted as one of the major challenges in the countries' health delivery systems. This has largely impacted on delivery at the primary level of care as the available personnel struggle to deal with huge workloads. In such circumstances, the delivery of palliative care in the clinic or health setting is compromised as the health professionals do not have adequate time to undertake comprehensive assessments or provide adequate psychosocial support. This situation is compounded by the lack of knowledge and skills in children's palliative care amongst the critical cadres in the health system.

Children's palliative care is not adequately covered in the pre-service curricula of nurses and doctors in all of the three countries. A recent situational analysis[27] of the status of integration of palliative care in Zimbabwe's pre-service curriculum noted that there was little coverage of palliative care in both the nursing and medical curricula. Health professionals interviewed across the three countries felt that there was a need to strengthen both the in-service and pre-service training to ensure wider coverage of children's palliative care services.

There are, however, efforts to strengthen pre-service curricula in the three countries, which include curriculum review and development with a focus being placed on communication as a core competency of undergraduate students, a skill that has previously been noted as lacking. For example, a Palliative Care Curriculum Development Working Group (PCCDWG) comprising palliative care practitioners, educationists and representatives from the MoHCC in Zimbabwe have been spearheading efforts to integrate palliative care in pre-service curricula. In South Africa, there are no specific examinable modules for children's palliative care in the curricula although there is some progress in introducing palliative care at different levels, particularly for the clinical years. For doctors there is a component of a placement at a local hospice or palliative care organisation during the 4th year of medical school, but this was seen as very limited.

> *"…but we have introduced it into the 3rd year where we are strengthening the clinical component and have also started bereavement counselling…in the 3rd, 4th to 6th year we build up palliative care all the way through. The minister said primary health care has to be strengthened so all we need to do is to bring that kind of training at that level…" Senior Lecturer, UKZN School of Medicine, SA*

Through the partnership between KEHPCA and the MoH, some strides have been witnessed in integrating palliative care teaching in the pre-service curricula in the last couple of years. In particular, palliative care is now integrated in the BSc Nursing curriculum and has specific hours set aside for some of the Universities, except for Nairobi University which reported difficulties in absorbing the additional training due to a full curriculum. KEHPCA has been offering some training to these students in order to

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[27] Situational Analysis on the Integration of Palliative Care in Tertiary Institutions of Zimbabwe, APCA/Island Hospice Service, 2011

bridge this gap. However, this training is not a mandatory course and does not affect their graduate qualification.

> *"So what we have been doing as an organisation when we have as much funding, when the medical students graduate we bring them in for two days and give them a crash programme on palliative care before they go out into the field because between the time they graduate and are posted they are usually idle. Last year some came and asked to be trained so there is a lot of interest." KEHPCA*

Training in CPC in Kenya was undertaken for two cohorts in 2012 through the technical and financial support of ICPCN, in partnership with KEHPCA. This training targeted a wide cross-section of professionals which included Paediatricians, Nurses, Psychologists, Pharmacists, Social Workers and other Palliative Care practitioners. A group was also seconded to attend a Training of Trainers course in South Africa and these have constituted the core team of local trainers for palliative care for children. The health professionals that were trained in these workshops felt that these were very helpful in providing insight into the need and the appropriate ways of dealing with children and their families. Furthermore, the trainings were regarded as having ignited initiatives to set up teams providing palliative care for children in some hospitals. Two paediatricians interviewed in this exercise received training and are now championing the setup of CPC service provision in their respective district hospitals.

In South Africa, a notable gap is that despite the individually driven efforts by the palliative care experts in a few selected tertiary institutions, there is minimal post-service palliative care training and mentorship programmes within the system. The CPC experts are in most cases overwhelmed with cases and can only provide limited coverage in terms of caseload and the institutions supported. The lack of mentoring was also noted to be a major gap in the current capacity building efforts. The need for enhancing the skills of breaking bad news and communication were emphasised. Both Kenya and Zimbabwe presented similar limitations in in-service training although there is evidence of progress. HOSPAZ, in partnership with the ministry in Zimbabwe, developed a Palliative Care for Children Training Manual which was adopted by MoHCC and has been used in providing trainings to different target groups including professionals. This manual was developed following a country wide survey on care and support and standards of care. More than 60 partners were trained using the manual. Currently a National Palliative Care Curriculum draft is with MOHCC whilst a draft training manual in line with this curriculum will soon be available.

Some health professionals in Zimbabwe noted that due to low staff numbers, which placed limitations on their time, was often the reason for their inability to provide comprehensive care and include other palliative care components such as detailed assessments, pain management, counselling and adequate communication with patient and family.

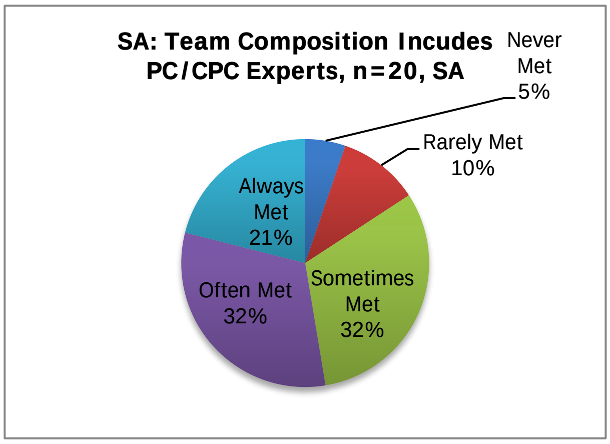
> *"I will tell you the truth, health care workers know about them [counselling, communication] but they are too busy for that. Because you can imagine I go to an HIV clinic and I am part of the team that runs the HIV clinic, you have one hundred patients a day, and how do I start listening? I want to but I have so many others waiting." Paediatric Consultant, Zimbabwe*

The lack of multidisciplinary teams within the public sector has also compounded the problem as the same respondent noted:

> *"So the system that works well have a social worker as part of the team, they have a psychologist, and I do my part and the psychologist will do their part. But if a doctor has to be the psychologist, and social worker it is not manageable but occasionally you will have that patient with so many problems, you just have to give them time." Paediatric Consultant, Zimbabwe*

The emphasis of a multi/inter-disciplinary team approach was evident amongst the organisations providing specialised care in the developed NGOs. In particular, all the private service providers had people as part of their teams focusing on nursing/medical care and those to deal with the emotional and psychological aspects. Teams therefore either had nurses and nurse counsellors or nurses and social workers, with the latter only present in the hospices. Personnel in the NGOs in most cases do not have adequate skills to provide holistic care to the children and fully address their needs. The majority have not received training in CPC. The numbers of personnel are also limited in these institutions and this has in most cases limited the reach and scope of their work.

Figure 18: Availability of Palliative Care Experts in Teams - SA



Although previous trainings provided by HPCA and ICPCN targeted a majority of the organisations, they were affected by staff attrition over the years. Staff members in these organisations, some of which received the training, have over the years been absorbed into the Government system, which offers more lucrative benefits (salaries and perks) compared to the NGOs. Whilst this might, at face value, present as an advantage to the public health system, the training received is usually not recognised within the system to warrant appropriate task allocations or deployment to relevant departments i.e. some nurses who previously received training in CPC are no longer attending to children in the health facilities.

In South Africa, CHWs providing care and support services and receiving allowances/stipends would have undergone a basic training in Home Based Care. The basic HBC training runs for 59 days and has key components of palliative care. Additional training in CPC is also provided to those willing to attend and several caregivers have received this training, particularly in Bloemfontein, under the hospice unit. The trained caregivers therefore present a critical mass of personnel with basic skills to provide community based palliative care services. Attrition of trained HBC Caregivers is rarely experienced, as the cadre is incentivised through a monthly basic stipend of 1,000 – 1 500 Rands ($100 - $150) per HBC Caregiver. In Zimbabwe, the CHWs undergo a nine-module training course over three weeks and receive monthly allowances of $14/$15 on a quarterly basis.

Though mainstreamed, particularly for Zimbabwe, the palliative care component of the basic HBC training is not adequate to fully equip the caregivers with the essential skills to provide holistic quality care for children, especially in the context of limited ongoing community based supervision and mentorship by skilled personnel.

4.4.4 CPC Medications and Materials

There have been significant improvements in the availability and accessibility of essential palliative care medications, including morphine, in the past years across the three countries. The 2010 report by

Human Rights Watch, *Needless Pain*[28], established that there was a lack of morphine in the government hospitals. This has since improved with the purchase of morphine to meet the national estimated need. Although there are occasional stock-outs of some medications, such as morphine, in South Africa, these usually do not go beyond two weeks and are not regular. Access to pain and symptom medications depends on whether the health workers prescribe the medications for the patients in need. Palliative care practitioners and paediatricians in the public facilities in Zimbabwe noted that there are still some periodic challenges in the availability of morphine. The palliative care situational analysis conducted in 2012[29] also reported that morphine was available in most facilities for use in cases of severe pain, although some occasional stock-outs were experienced. It seemed from the discussions that the situation on morphine availability is to a large extent similar to the general trends in the availability of other essential medications.

The main challenge that was highlighted regarding medications for CPC was that health professionals were generally hesitant to prescribe morphine, particularly to children, due to the various myths surrounding its use. Despite the occasional stock-outs and "dry" periods, this reluctance to prescribe and/or administer morphine was noted as a major barrier to effective pain management. The lack of adequate knowledge amongst health professionals and their related fears and negative attitudes were commonly mentioned by respondents in the three countries. Respondents provided a common opinion that there is a need to provide relevant education to both professionals and the public. The NGO hospices and palliative care organisations reported working with public health facilities to ensure access to medications for their patients.

> *"It is very low and I think health workers need to be capacitated. Generally health workers are "scared" of morphine and we ask them to give a child morphine they do not want to. So I think the use is quite low and there was a time the hospital was not ordering it so we motivated and advocated and they brought it. They actually complained at some time that it was not being used but it is different for surgeons and anaesthetics so the use is very low." Paediatrician, Zimbabwe*

> *"Firstly, the pharmacists say it is not being prescribed and there is no need, of course there are other competing priorities so again the availability for me is more connected to lack of awareness in those areas. I remember in one hospital ward the morphine had expired and the reason was because it was not being prescribed so you find in the end the pharmacists in those hospitals will not procure it because it is not being prescribed." PC Doctor.*

There was continued reference to the lack of knowledge, fears and lack of appreciation of the need to prescribe morphine amongst health professionals as is illustrated in the diagrams depicting common terms used in describing the gap in intention to use morphine amongst professionals.

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[28] Needless Pain, Human Rights Watch, 2010

[29] Zimbabwe National Palliative Care Situational Analysis Report, MoHCC, 2012

Figure 19: Key Terms Describing Reasons for Low Uptake of Morphine Use

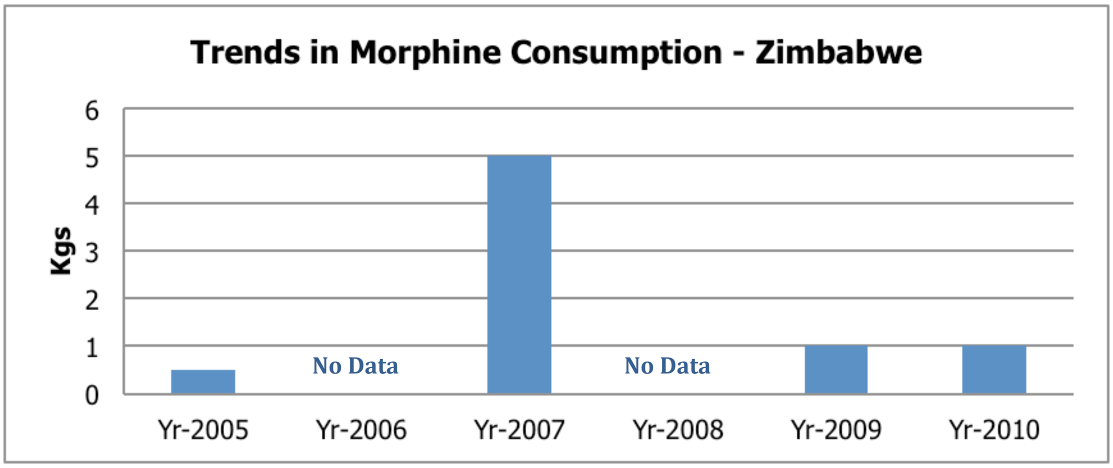
The fears are compounded by the policy regulations on morphine prescribing. The National Medicine's Policy in Zimbabwe requires that opioids be prescribed by medical doctors whilst nurses can only prescribe mild analgesics in special circumstances. Morphine consumption in Zimbabwe has largely remained low as indicated by the chart below. The 2009 and 2010 estimates of 1kg annually translate to a very low morphine per capita rate. It was observed that doctors and nurses in Kenya have a very good course on pharmacology so its lack of use is more to do with their perception of the risks, and attitudes in practice. Efforts to address the lack of knowledge, myths and attitudes are mainly in the form of training and awareness. Nairobi Hospice in conjunction with KEHPCA as well as HOSPAZ and Island Hospice in Zimbabwe are running various training workshops. The Kenyan edition of ehospice had plans to address the resistance by some professionals to prescribing morphine.

> *"Where we did the training we noticed there was a rise in the appropriate consumption of morphine and it was low in those that were not trained." PC Paediatrician*

> *"…also I think it is not just about availability but training. I think some of the health care workers do not feel comfortable or are not trained to provide these medications to paediatric populations and they have not received the kind of training we would want them to have and so there are cases I have seen where the drugs are available but are not used, practitioners do not feel confident in providing them." Key Informant, HIV and AIDS Organisation, SA*

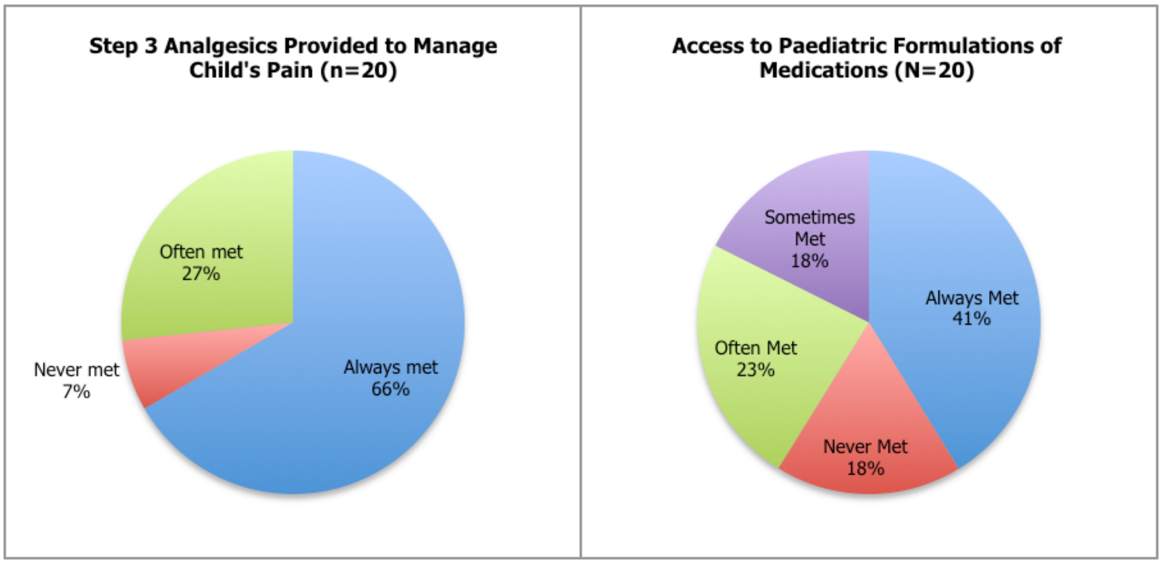
The national umbrella bodies, KEHPCA, HPCA and HOSPAZ were seen to be pivotal and active in ensuring essential palliative care medications are recognised within the system and are made available. The medications are included in the national clinical guidelines and essential medications list - Essential Drug List of Zimbabwe (EDLIZ), Kenyan Essential Medicines List (KEML) and the Essential Drug List of South Africa. Policy makers generally felt that the presence of medications such as morphine in clinical guidelines should also be leveraged in changing the perceptions of health workers on its use. In addition, a number of health professionals also emphasised that it will be equally important to educate the community so that there is informed demand creation.

Figure 20: Morphine Consumption in Zimbabwe



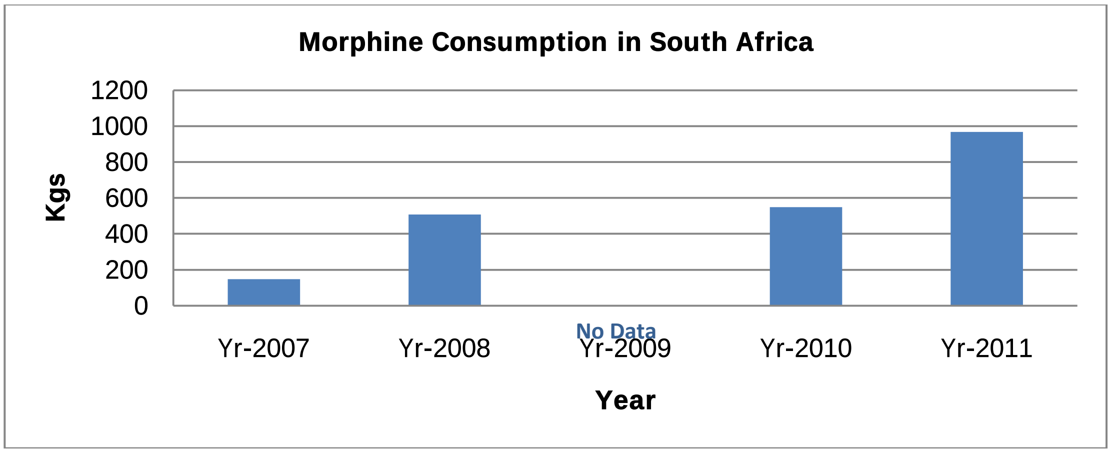
Data Source: UN: International Narcotics Control Board (INCB), 2011

Figure 21: Access to Analgesics and Paediatric Formulations and Usage in South Africa



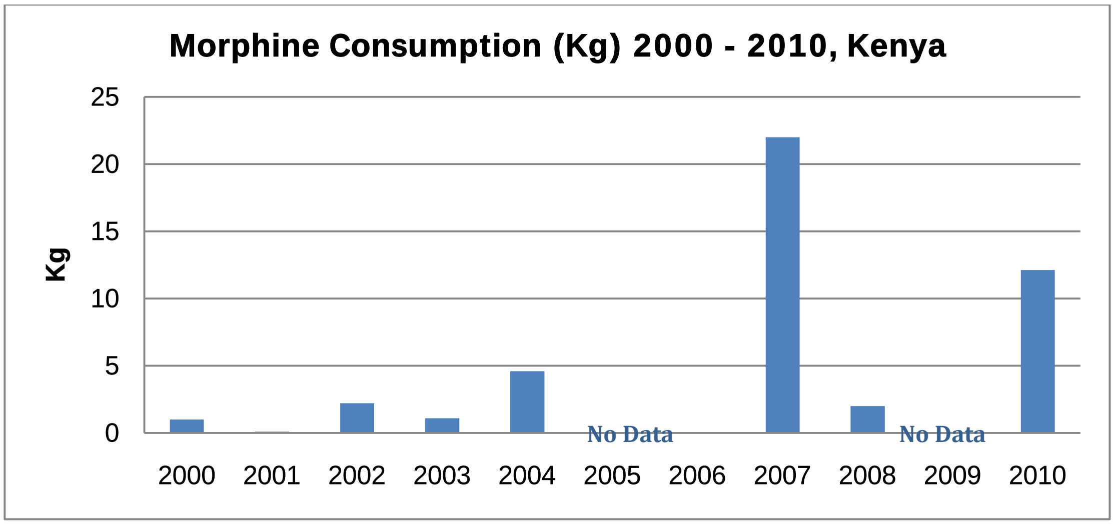
The graph below shows that morphine consumption in South Africa has generally increased in the past years.

Figure 22: Morphine Consumption - South Africa



Data Source: UN International Narcotics Control Board (INCB), 2011

Figure 23: Morphine Consumption - Kenya



Data Source: UN: International Narcotics Control Board (INCB), 2011

4.4.5 Financing of CPC Services

There is very limited funding for CPC activities in all the countries. Domestic financing through the central Government is still minimal whilst external funders and donors have placed their priorities on the key interventions that are seen to directly address the Millennium Development Goals.

In Kenya, the government has increased its commitment towards supporting palliative care activities through the development of the PCUs. The system is therefore funding palliative care personnel through these PCUs. Funding for the establishment and current implementation of the PCUs is being provided by KEHPCA through its partnership with the Diana Princess of Wales Memorial Fund and True Colours Trust under the Waterloo Coalition. This funding is focusing on integration through the training of health personnel in palliative care and the set-up of the PCUs. However, in the medium to long term it is envisaged that the continued sustenance and scale-up of the model would rely on either domestic financing or additional resources, which are still to be sourced. There is strong evidence of tangible financial support from the government towards palliative care activities within the system but it is unclear if these would match the actual need as discussed in the earlier sections.

In Zimbabwe, the Ministry, with the support of its development partners, is working towards strengthening the system using an all-inclusive approach that looks at all the pillars of the system. Partners have pledged their commitments and have provided support to the government through both technical and financial assistance. Whilst the GoZ, through the Ministry, is currently a recipient of various grants, none have been committed towards palliative care activities. The majority of the financial support has been directed towards specific disease programmes directly falling under interventions for MDGs, such as HIV and AIDS and Maternal, Neonatal and Child Health. Of note, international and multilateral partners have pooled resources to finance a programme under the Health Transition Fund, aimed at strengthening the health system in the context of MNCH. Similarly, the World Bank has been supporting the GoZ with a grant of $35M for a Health Results Based Financing (HRBF) Programme also looking at addressing MNCH problems. The Global Fund has traditionally been supporting the government in the area of medications as well as community system's strengthening. Securing additional GF rounds has become increasingly difficult and, like other countries, this has been seen to be a huge threat to the gains previously realised in HIV and AIDS programming. Some respondents, particularly funders and policy makers, felt the focus on HIV and MNCH was highly justified in view of the high HIV prevalence and Maternal Mortality Ratio of 960 per 100,000[30] live births against the 2015 MDG target of 145 per 100,000 live births.

In South Africa, organisations with the home-based care component have benefited from the CHW stipends provided by DoH/DoSD. However, there are some concerns amongst some care providers that the model and nature of this support is unsustainable and that at some point the system may fail to continue providing incentives and material support to the caregivers.

"But somehow it's not sustainable because some months they don't pay, particularly in between the one year contracts [renewal] there may be 2 or 3 months they don't pay…" PC Service Provider working with HBC Workers

Under the Community System's Strengthening programme in Zimbabwe, at least 60 CHBCs in each district received training and support for service delivery of which one of the nine modules of their training is for palliative care. The caregivers receive a monthly allowance of $15, which is disbursed quarterly ($45). The programme is largely viewed as having enhanced access to palliative care at the primary level. HOSPAZ is also a grant recipient in which they support other HBC organisations as sub-grantees. The main NGO hospices reported facing huge challenges in funding. There is a crosscutting perception amongst the hospices and palliative care organisations that their current efforts are constrained due to resources. A medical doctor who was interviewed in the study noted:

"All you need to do is look at the operating environment in Zimbabwe then you will get the answer. The heart is there but the resources are not there, when the heart is willing the flesh is weak [laughs]." PC Doctor

The NGOs and welfare organisations providing palliative care are faced with a challenge of convincing potential funders to fund service delivery. The operations of these organisations are almost in all cases funded by external funders. This was viewed by some as bringing some concern on the sustainability of these initiatives especially in view of the reduced funding from partners such as The Diana, Princess of Wales Memorial Fund. Officials from Island Hospice noted that they had experienced one of their worst years regarding funding as an organisation. In South Africa some rely on local corporate organisations through Corporate Social Responsibility (CSR) programmes. The corporates' investment options are usually guided by the country development priorities as outlined by the Department of Social Development and DoH and since palliative care does not exist in these lists, very few organisations consider supporting these NGOs. For the past 6 years nearly all palliative care organisations under HPCA were getting support from PEPFAR grant through the HPCA. This grant is however coming to an end this year, 2013. HPCA has recently received confirmation of a very large grant towards integrating palliative care into the health care system from PEPFAR.

All the hospices visited during the study mentioned that they were facing serious challenges to finance their activities. They attributed these to a dwindling donor base, approvals restricted to small grants for short-term projects, a general shift in the strategic focus of donors and the lack of awareness of palliative care amongst funders. The hospices felt that with the increasing focus on systems strengthening and integration they risked being forgotten by funders as everyone will focus on supporting government programmes. In addition, those conducting training also highlighted that there

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[30] Zimbabwe Demographic and Health Survey 2010/11 Report, ZIMSTAT, 2012

seemed to be inadequate space to source funding for these as the umbrella body, which also provides training, will always be preferred by funders.

KEHPCA, as a national umbrella body actively seeks funding from various funders to support their strategic framework and this is mainly through proposal writing. Some of the funders include ICPCN, the Diana Princess of Wales Memorial Fund, True Colours Trust and Hospices Kenya. Most of the funding that the national body has been seeking is focused on training and integration of palliative care into the health system. KEHPCA is currently does not have a grant disbursement and management function. At present, the activities or programmes of the hospices are purely donor funded and based on technical and financial proposals. Occasional support with unrestricted funds or material support is also received from local donations, friends of hospices and international twin-partnerships.

Some hospices have improvised by introducing a fee for their services. This is a change from their traditional model of being donor funded and providing free services thus ensuring that even the poor have access to the service. Nairobi Hospice has now introduced a consultation fee of 200 Kenyan Shillings (≈US$2.35). Island Hospice Service Harare has also introduced a policy of cost sharing although the amount to be contributed by the client is left to the clients' discretion. Though the amounts paid may not seem huge, it might be worth reviewing its effect considering that the average out of pocket expenditure (% of total expenditure on health) for 2009, 2010 and 2011 were 43.7%, 45.8% and 46.4%[31] in Kenya and this signifies the high prevalence of catastrophic health expenditure in the population. Patients seeking palliative care services are in most cases also seeking other health care services, which may require payments. Despite the full implementation of a National Health Insurance Fund in Kenya, it is widely believed that a majority of individuals are not able to contribute to the insurance scheme as they are not employed. The move to introduce user fees for hospice and palliative care services may therefore introduce inequities in access to this essential service. There is therefore a notable funding gap for palliative care activities for the hospices and palliative care organisations.

4.5 Study Limitations

A significant number of limitations should be noted in the course of conducting this research. We were unable to find any previous estimates of the need for children's palliative care in low and middle-income countries that did not rely exclusively on mortality data. Thus this report breaks new ground and does not have the benefit of previous work for comparative purposes.

We relied mainly on secondary data sources and had to rely on the accuracy of that data. IHME and WHO generated most of the prevalence and mortality data for these three countries from population estimates. Well functioning patient registries and accurate death certificate data is not available. HIV prevalence data from UNAIDS is somewhat more reliable but are still estimates.

The use of pain prevalence as a marker for palliative care need is a blunt tool that probably underestimates the need for palliative care. There are many more symptoms besides pain that call for palliative care intervention and research on pain prevalence is variable and limited. Further we do not have good evidence for pain prevalence in children as distinct from adults. Similarly the use of 37.5% as a need for specialised palliative care may not be accurate. Australia has a well-developed palliative care delivery system while our study countries have very limited capacity to deliver primary palliative care. Further research is needed on the proportion of children and adults that have more complex needs for palliative care. As there was very little additional evidence in the literature, the conservative figure of 37.5% figure was used.

The need for palliative care in certain conditions may be understated, particularly for neonatal and neurological conditions, and DR-TB. There is a growing movement to deliver palliative care to neonates

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[31] World Development Indicators, World Bank

and infants who are likely to have very short lives, however we have excluded most of these children in agreement with WHO as so many of these deaths are preventable. However a child's life is precious even if it lasts for only a day and these infants also require palliative care. Limiting to only DR-TB excludes many children that die from regular TB and we think neurological conditions may be under reported. It was also difficult to assess the numbers of children with specific disorders such as thalassemia since the prevalence data did not include that level of detail in the sequela.

In the capacity assessment there likely to be some subjectivity as providers were asked to report on their self-assessments of service capacity.

Finally, we have adjusted the findings for variation in length of survival. Using an overall average length of service is a general calculation. A more accurate method would be to use and weight ALOS for each condition; however that ALOS data is not available at present.

Other aspects to note are:

- Very few interviews (one in each country) were held with representatives of International Agencies and Donors as those targeted were either not available or had conflicting schedules during the periods for in-country data collection. The funder's perspective is therefore not adequately covered in this report.
- The approach to electronically distribute the Capacity Self Assessment Tool resulted in a low response rate for that component of the study. This generally weakens the generalisability of the capacity assessment although the qualitative interviews do, to a large extent, help to provide a broader picture of the capacity aspects. Discussions on capacity therefore make reference to both data sources.

5 Conclusions and Recommendations

5.1 Conclusions

- The report describes the development of methods for assessing the need for and capacity to deliver CPC in Kenya, South Africa, and Zimbabwe.
- The following table summarises the estimated population need for CPC in the three countries. We distinguish between the overall need for those that can benefit from CPC from those within that group that can be expected to have a need for specialised palliative care services. The larger group's needs should be met in the primary health care system while the latter is an indication of the real on-going need for CPC services. The need for CPC in these countries is 3.75 to 5.6 times higher than has been documented in research on the need for CPC in the UK.

Table 9: Estimates of the Generalised and Specialised Need by Country

Country	Generalized CPC Need	Specialised CPC Need	Population %	Rate per 10,000 Children	Average Daily Census
Kenya	660,717	264,102	0.68	120.05	72,357
S. Africa	801,155	304,441	0.62	151.92	83,409
Zimbabwe	312,046	117,231	0.91	180.63	32,118

- A major finding of this study is that the number of children benefitting from palliative care services in the three countries is significantly low in comparison to the estimated need. Based on the statistics provided by the NGO hospices and palliative care organisations and the estimated reach in the public facilities, the number of children reached with palliative care services in 2012 is 14,501 in South Africa (less than 6% of specialised need), 545 in Kenya (less than 1% of the specialised need), and 5,438 in Zimbabwe (~5% of specialised need). Thus the gap between need for and provision of specialised CPC in these countries is very large.
- Service providers and other stakeholders in palliative care agree that the need is not being acknowledged; that the need for CPC goes beyond HIV and AIDS and cancer but also includes other conditions that are life limiting and life threatening to children including cardiovascular disease, congenital anomalies, neonatal conditions, endocrine disorders, and other conditions.
- The current response to this need is evident within the public health system and the complementary hospice and palliative care organisations. There are efforts to ensure palliative care is integrated, particularly at the primary level of care. Expert palliative care providers do exist at the tertiary level and are providing services at various Government institutions. There are hospices and palliative care organisations providing palliative care to children either exclusively through either directly targeting children or by integrating with adult palliative care and hospice care.
- The extent to which the response is adequately addressing the palliative care burden is limited due to a number of factors that are related to organisational capacity.
- Palliative care is not positioned as a high priority in national policy and strategic frameworks, despite its reference and recognition in various documents or provincial level strategic actions. This therefore limits this health issue from being fully integrated within the public health delivery system, leading to further barriers in terms of being a priority within national health budgets. Specific components of palliative care are not being fully provided in both the public health system and by the palliative care/hospice organisations, though for the latter there is some evidence of holistic care provision. Of note are lack of pain and symptom control, communication with children and families (including breaking bad news), death awareness and preparation. There is some over focus on physical symptom management with limited psychological, spiritual and social support.
- The numerical inadequacies of personnel in the public health sector, staff attrition in the hospice and palliative care organisations, limited knowledge and skills coupled with the absence of adequate mentorship have all been noted as the key human resource gaps for CPC provision which have also contributed to a compromised package of care.
- Essential palliative care medications were noted to be available and recognised in the pharmaceutical supply chain of the three countries. However, in all of the three countries the reluctance of health workers to prescribe and/or administer morphine was cited as a major barrier to access to comprehensive pain management.
- The decline in financing for palliative care services let alone CPC is apparent. The key inhibitors to financing are the low level of prioritisation of palliative care/CPC at national level. This was reported to have a strong influence on the priorities of corporate social investments, which have been a major source of funding for Hospices/Palliative care organisations.

5.2 Recommendations: Strategic Issues for Consideration

1. **Integration:** To bridge the gap in provision of palliative care for children integration into the public health system will be essential. This should be centred on funding of posts, adoption of palliative care team models at the primary, secondary and tertiary levels. Efforts to integrate palliative care in the broader health system need to be strengthened and strategies need to be underpinned on the public health model and use a health system's strengthening approach. Current efforts seem to be more focused on service delivery and human resources (training).

Additional focus is required at policy level, funding of palliative care posts and activities as well as ensuring adequate inclusion of palliative care indicators in health management information systems.

2. **PC Education:** Expansion of children's palliative care education is vital to ensure a wider dissemination of knowledge and skill in palliative care. However, it will be paramount to consider the appropriateness of the training and mentorship models. Some respondents suggested that these have to be customised to settings (hospital, hospice) as well as to the target group. The traditional palliative care training that recognises delivery of palliative care over some time may not be suitable for the cases in emergency settings. There is need for continued training of health workers in palliative care. Integration of palliative care in the pre-service curricula is to be prioritised to facilitate numerical adequacy in palliative care skilled health workers.
3. **Demand Creation:** It is essential that health providers include "demand creation" activities as part of their programmes. These primarily should focus on awareness raising and also training of community organisations to ensure the population is aware of available children's palliative care services and where these can be found.
4. **Funding:** It is of utmost importance that children's palliative care is prioritised on the development agenda by funders. Palliative care has a significant role in addressing the global development goals on HIV and AIDS, Child Health and Maternal Health.

5.3 Next Steps

1. Now that a method for estimating the need for CPC has been developed for these three countries the next logical step would be to conduct an analysis for the rest of the countries in the world that would allow a more accurate estimation of the global need for CPC.
2. This study developed several methods for carrying out an assessment of the capacity to provide CPC. A further step would be to provide a set of tools for countries to conduct their own capacity assessments against the need in their country to measure the gap in provision of CPC.
3. If the provision of CPC is to be encouraged and the gap closed, a great deal of further work is needed to provide the skills needed to develop specialised CPC services and to train service providers from multiple disciplines to deliver palliative care to the millions of children that have a right to receive it.
4. Further research is needed to improve on the estimation of need for CPC, and on children's understanding of death and dying, pain management in general and in the absence of strong opioids, interventions and outcomes of care, and ethical and children's rights issues.

Appendix 1: Key Informant Interview Guide - Service Providers

Assessing the Need for Palliative Care for Children

Introduction

My name is _______________, I am a consultant working with (specify country's local coordinating body - HOSPAZ/HPCA/KEHPCA), UNICEF and the International Children's Palliative Care Network in a joint analysis to assess the need for palliative care for children. The purpose of this assessment is to establish the extent of the need for paediatric palliative care as well as the current response and gaps in meeting the need. Findings of this exercise are expected to contribute to the crafting of an investment case for paediatric palliative care and provide a platform for learning in order to strengthen the current response. Your selection to participate in this exercise has been purposive due to your involvement in providing services to this target group. All the information you will provide will be kept confidential and will be used only for the above purpose. Your co-operation in this regard will be highly appreciated. You join this exercise at your free will and can withdraw anytime you may wish, should you feel uncomfortable or find the questions upsetting. The interview will take approximately 45 minutes to complete. **(*Go to consent form*)**

Background Details of Respondents

Name of Institution/Facility	
Name of Key Informant	
Designation at Institution/Unit	
Period with Institution (Yrs/Months)	

Instructions for Moderator:

1. This guide should help you to initiate and carry forward the discussion.
2. It should flow like a normal discussion, than a usual questions-answers session.
3. The questions need not be followed chronologically. But, before completing the discussion, please make sure that all the points in the guide have been covered.
4. The respondents should be comfortable and in a mood to sit with you for about 45-60 minutes at least. If this is not possible, please request for another schedule.
5. Start the discussion by talking about general things related to work and life. Please ensure privacy for this discussion.
6. While discussing about the services, please encourage to talk about the critical gaps that could be existing in addressing the need

Section One: Perception of the need for palliative care for children

a.	What is your perception of the need for palliative care for children in your community and/or country? ***Probe:*** Magnitude of the need and reason?
b.	What do you mainly attribute the current need to? ***Probe:*** Which diseases do you feel contribute the most to the cases requiring PPC?
c.	How would you describe the spread of the need in the country? ***Probe:*** Are there specific groups or locations that present with a notably higher need?
d.	Have changes in availability of HIV treatment affected the need for palliative care services, and if so how ?

Section Two: Service delivery

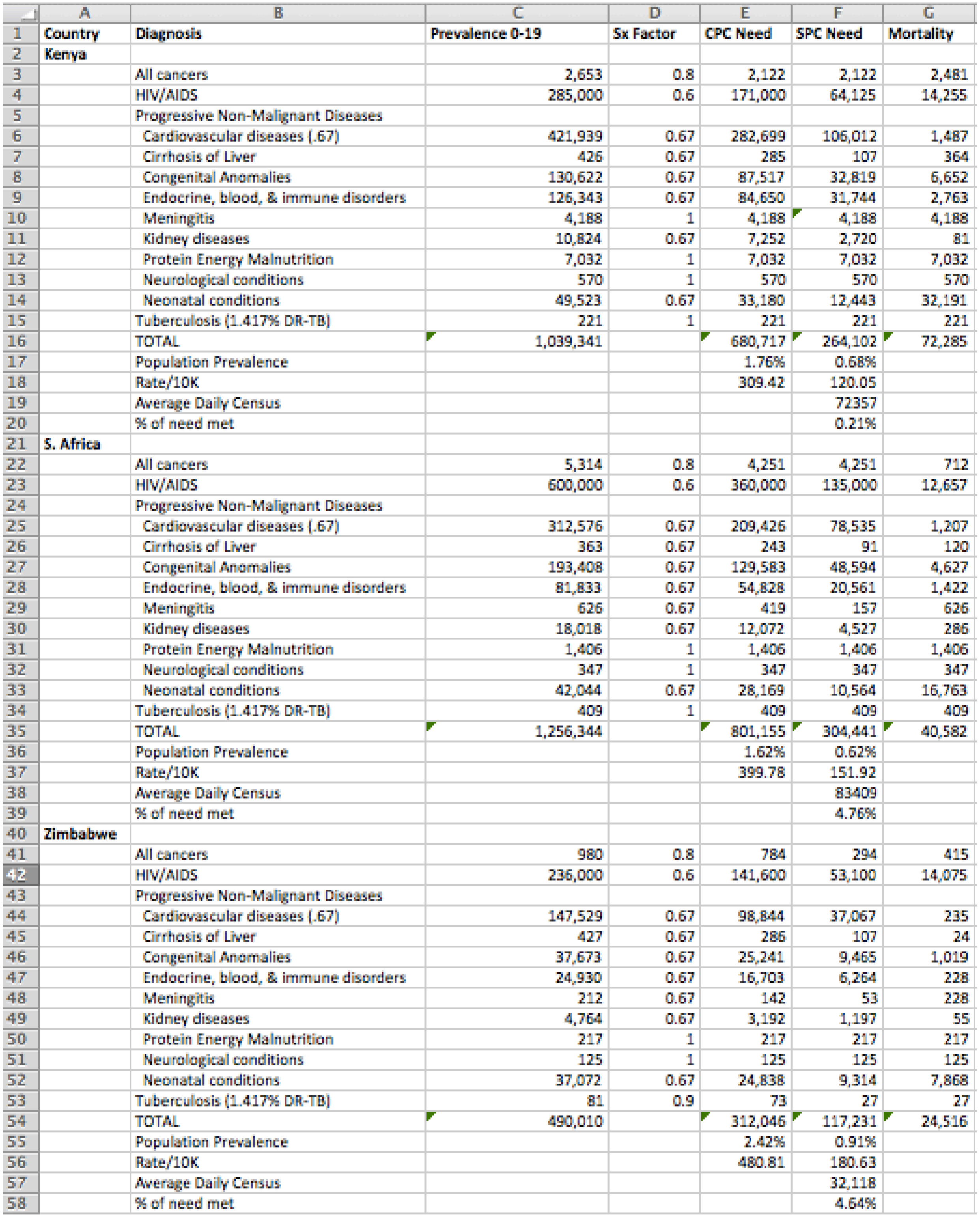
a.	What services are you currently providing to children requiring PC? **Probe:** Are these clinical, focusing on physical, psychological, social and spiritual aspects?
b.	To what extent are family members involved in the care of children requiring palliative care? How is this done and what support do you provide to primary caregivers within the family?

c.	How do children and their families participate in care decisions? **Probe:** Does the organisation/unit provide basic information regarding the care and treatment proposed?
d.	How do you ensure continuity of care for your clients? Does the team have clear instructions about the ongoing management of the child's pain and symptoms, and know when to refer to higher-level service providers?
	Where households are facing economic difficulties or problems getting adequate food and nutrition – how do you respond – either directly or through referrals?
e.	How are end of life issues and anticipating death dealt with?
f.	What support systems are in place to ensure emotional and bereavement support for children can be provided to those who need it?
g.	What is your geographical coverage of services? **Probe:** Is your service provision localized or spread across the country?
h.	How many children benefitted from your services in the past year (2012)? *Request for any documents if available. Disaggregate direct and indirect.*
Section Three: Policy and strategic framework	
a.	What policies are you currently using to guide your service delivery? **Probe:** Is there a national palliative care policy? Does this policy address children's palliative care issues?
b.	To what extent is paediatric palliative care considered and addressed in the national health strategy? ***Mainly applicable to national bodies***
c.	To what extent is PPC considered in your institution's strategy? ***Probe:*** Is there specific mention of PPC and recommended response strategy?
d.	What are the roles and functions of the MoHCW, national body and service providers in PPC service provision in the country? ***Probe:*** Are the roles, functions and inter-linkages clearly defined and communicated?
Now let us take a moment to look once again at the services but paying attention to capacity issues relating to human resources, pharmaceuticals and funding…	
Section Four: Human resources: - numerical adequacy and education	
a.	What is the institution/unit's current staff compliment attending to children? **Probe:** Fulltime, volunteers. Ratio of children under care to staff
b.	What is the multidisciplinary nature of the staff compliment (doctors, nurses, social workers, psychologists etc) to support the assessment and management of the child's pain, symptoms and psychosocial needs?
c.	How many of the staff members received basic training on the principles, objectives and practices of palliative care for children? Probe: Who provided training and when?
d.	How regular is training and mentorship in the psychosocial needs of children and their families provided to staff and other partners?
e.	How would you regard the staff's knowledge of the rights of the child and their family, along with the organization's responsibilities as identified in laws, charters and regulations?
f.	What are the felt and/or perceived training needs relating to caring for children requiring palliative care amongst staff in this institution/unit?
Section Five: Pharmaceuticals: - essential palliative care medications	
a.	What paediatric palliative care medications do you require on a regular basis in your institution or unit? Probe: Do you access these regularly?
b.	What are the main sources of these medications? Do you have access to morphine for pain management? Probe: Did you experience any stock outs last year and if so for how long?
c.	What challenges have you faced in accessing medications for pain and symptom control for PPC clients?

d.	In what ways do you feel access to essential palliative care medications may be improved?
Section Six: Financing of paediatric palliative care services	
a.	How are you currently financing the PPC service provision? ***Probe:*** Are you relying on specific project funds or donations?
b.	To what extend is your current funding adequately covering the resources required for optimal delivery of services for PPC? Probe: where do you see the major needs and gaps?
c.	Have you seen any significant changes in the levels of funding for palliative care over the last 5 years
d.	Does your institution/unit have a resource mobilization strategy that caters for PPC? ***Probe:*** Do you write any project financing proposals that specifically target children in need of palliative care?
e.	What challenges have you faced in mobilizing resources to support PPC activities?
Section Seven: General comments	
a.	What other challenges have limited the reach and quality of your palliative care services to children?
b.	Any other comments?

Thank you for your valuable time and contributions to this assessment

Appendix 2: Summary Table of Calculation of Need for Children's Palliative Care



	A	B	C	D	E	F	G
1	Country	Diagnosis	Prevalence 0-19	Sx Factor	CPC Need	SPC Need	Mortality
2	Kenya						
3		All cancers	2,653	0.8	2,122	2,122	2,481
4		HIV/AIDS	285,000	0.6	171,000	64,125	14,255
5		Progressive Non-Malignant Diseases					
6		Cardiovascular diseases (.67)	421,939	0.67	282,699	106,012	1,487
7		Cirrhosis of Liver	426	0.67	285	107	364
8		Congenital Anomalies	130,622	0.67	87,517	32,819	6,652
9		Endocrine, blood, & immune disorders	126,343	0.67	84,650	31,744	2,763
10		Meningitis	4,188	1	4,188	4,188	4,188
11		Kidney diseases	10,824	0.67	7,252	2,720	81
12		Protein Energy Malnutrition	7,032	1	7,032	7,032	7,032
13		Neurological conditions	570	1	570	570	570
14		Neonatal conditions	49,523	0.67	33,180	12,443	32,191
15		Tuberculosis (1.417% DR-TB)	221	1	221	221	221
16		TOTAL	1,039,341		680,717	264,102	72,285
17		Population Prevalence			1.76%	0.68%	
18		Rate/10K			309.42	120.05	
19		Average Daily Census				72357	
20		% of need met				0.21%	
21	S. Africa						
22		All cancers	5,314	0.8	4,251	4,251	712
23		HIV/AIDS	600,000	0.6	360,000	135,000	12,657
24		Progressive Non-Malignant Diseases					
25		Cardiovascular diseases (.67)	312,576	0.67	209,426	78,535	1,207
26		Cirrhosis of Liver	363	0.67	243	91	120
27		Congenital Anomalies	193,408	0.67	129,583	48,594	4,627
28		Endocrine, blood, & immune disorders	81,833	0.67	54,828	20,561	1,422
29		Meningitis	626	0.67	419	157	626
30		Kidney diseases	18,018	0.67	12,072	4,527	286
31		Protein Energy Malnutrition	1,406	1	1,406	1,406	1,406
32		Neurological conditions	347	1	347	347	347
33		Neonatal conditions	42,044	0.67	28,169	10,564	16,763
34		Tuberculosis (1.417% DR-TB)	409	1	409	409	409
35		TOTAL	1,256,344		801,155	304,441	40,582
36		Population Prevalence			1.62%	0.62%	
37		Rate/10K			399.78	151.92	
38		Average Daily Census				83409	
39		% of need met				4.76%	
40	Zimbabwe						
41		All cancers	980	0.8	784	294	415
42		HIV/AIDS	236,000	0.6	141,600	53,100	14,075
43		Progressive Non-Malignant Diseases					
44		Cardiovascular diseases (.67)	147,529	0.67	98,844	37,067	235
45		Cirrhosis of Liver	427	0.67	286	107	24
46		Congenital Anomalies	37,673	0.67	25,241	9,465	1,019
47		Endocrine, blood, & immune disorders	24,930	0.67	16,703	6,264	228
48		Meningitis	212	0.67	142	53	228
49		Kidney diseases	4,764	0.67	3,192	1,197	55
50		Protein Energy Malnutrition	217	1	217	217	217
51		Neurological conditions	125	1	125	125	125
52		Neonatal conditions	37,072	0.67	24,838	9,314	7,868
53		Tuberculosis (1.417% DR-TB)	81	0.9	73	27	27
54		TOTAL	490,010		312,046	117,231	24,516
55		Population Prevalence			2.42%	0.91%	
56		Rate/10K			480.81	180.63	
57		Average Daily Census				32,118	
58		% of need met				4.64%	

Appendix 3: Children's Palliative Care Capacity Assessment Tool

This audit tool for children's palliative care services is adapted from the African Palliative Care Association's APCA Standards Audit Tool. It is intended to help providers to self assess their capacity to provide children's palliative care as a part of a research project titled: **"Three Country Assessment of Palliative Care Needs in Children."** This research project is sponsored by UNICEF and ICPCN. Please complete the attached Informed Consent Form prior to completing this questionnaire. If you have any questions please contact the investigators noted on the consent form. Thank you very much.

Background Information

I. Name of organisation: ____

II. Country and city: ____

Position of person completing the tool: _________________________________
Telephone number (including country code): ______________________________

III. Email address of contact person: ____

VI. Type of organisation: For the options below, please tick the appropriate box that best represents the type of PC organisation/ service.

1. Hospice/ PC Organisation ☐
2. National PC Association ☐
3. PC Country Team ☐
4. HBC Organisation ☐
5. Public Hospital/ Health Facility ☐
6. Private Hospital/ Health Facility ☐
7. Other NGO involved in PC Please list ☐

____

8. How many children (0-18 did your organization care for in the last year? _______________

9. Please identify the major barriers to providing children's palliative care that you experiencing:

____
____
____

CPC Provider Capacity Self-Assessment Tool from African Palliative Care Association Standards

PRINCIPLE 3: CHILDREN’S PALLIATIVE CARE

Standard 3.1: Holistic care provision in children

Standard Criteria/Quality Elements	1-Never met	2-Rarely met	3-Sometimes met	4-Often met	5-Always met	Evidence	Total Score
1 Primary/ Basic Level							
The unit of care is the child and their family.							
Professional care providers have received basic training on the principles, objectives and practices of palliative care for children.							
Community care providers are supervised by a professional care provider who has had basic training in the principles, objectives and practices of palliative care for children.							
The palliative approach is adopted by professional care providers incorporating a concern for the holistic needs of the child, including the needs of the family, and is based on an open							
Families refer themselves to level 1 service providers for support with the care of their							
One person from the service provider is identified as the family’s key worker and contact							
Grand Score							
2. Secondary/ Intermediary Level (All of level 1 plus)							

Palliative care for the child and their family is provided by an inter-disciplinary team of health providers who have been trained and are knowledgeable and skilled in children's palliative care							
There are appropriate links between different levels of service provision to enable the child and their family to access expertise, irrespective of the geographic location or size of the service.							
Grand Score							
3. Tertiary/ Specialised Level (All of level 2 plus)							
The provision of palliative care to the child is supervised by a specialised children's palliative care provider.							
The composition of the team providing palliative care for the child and their family includes specialised palliative care providers as well as specialised children's care providers, drawn from a range of disciplines that will enable the service to meet the cultural, physical, psychological, social and spiritual needs of the child and their family.							
The team's expertise in children's palliative care helps to inform education, training and research as well as practice, and is shared where possible with level 1 and 2 service providers.							

Mentorship and training is provided to level 1 and 2 service providers.							
The team of carers providing for the child and their family are provided with psychosocial support and supervision, and where required will offer this service to level 1 and 2 service providers.							
Grand Score							

Standard 3.2: Pain and Symptom Management for Children

Standard Criteria/Quality Elements	1-Never met	2-Rarely met	3-Sometimes met	4-Often met	5-Always met		
1 Primary/ Basic Level							
Community care providers undertake a basic assessment of the child's pain and symptoms and seek help or advice when needed.							
Professional care providers undertake a basic assessment of the child's pain and symptoms, and provide basic pain and symptom management.							
There is routine access to step 1 analgesics, and to step 2 and 3 analgesics under the guidance of level 2 and 3 service providers.							
Care providers have clear instructions about the ongoing management of the child's pain and symptoms, and know when to refer to level 2 and 3 service providers.							

There are written instructions for managing pain 'by the clock' and for giving breakthrough analgesics as required.							
The care providers have clear instructions about how to seek help from level 2 and level 3 service providers if needed, in particular out of normal working hours.							
Non-pharmacological as well as pharmacological methods of pain and symptom management are provided.							
Referral networks are in place to level 2 and 3 service providers to ensure that there is clinical support for the child when needed.							
Grand Score							
2. Secondary/ Intermediary Level (All of level 1 plus)							
Professional care providers undertake a comprehensive assessment of the child's pain and symptoms.							
Effective pain and symptom management is provided.							
There is routine access to step 1 and step 2 analgesics, and step 3 analgesics under the guidance of a level 3 service provider.							
There is an inter-disciplinary team available to support the assessment and management of the child's pain and symptoms. This includes the treatment of the underlying cause of any symptoms as appropriate, alongside the management of that symptom.							

Side-effects of medications are anticipated and actively treated as appropriate.							
Referral networks are in place to level 3 service providers to ensure that there is clinical support for the child when needed.							
Grand Score							
3. Tertiary/ Specialised Level (All of level 2 plus)							
A comprehensive plan of care for the assessment and management of the child's pain and symptoms is developed.							
Support is given to level 1 and 2 service providers in order to ensure that the plan of care is followed regardless of the setting of care.							
Step 3 analgesics are provided as appropriate to manage the child's pain as part of a comprehensive programme for pain assessment and management.							
There is access to paediatric formulations of medications and a clear system in place to enable the child to access these formulations regardless of the place or level of care.							
Complex pain and symptoms in children are assessed and effectively managed.							
Leadership regarding the provision of pain and symptom control in children is provided							
Referrals from level 1 and 2 service providers are received and managed with regards to pain and symptom management in the child.							

Referring back and ongoing support take place as required to ensure that the child receives good pain and symptom management regardless of the place of care.							
Training and mentorship in pain and symptom assessment and management in children are given to level 1 and 2 service providers.							
Grand Score							

Standard 3.3: Psychosocial care for children

Standard Criteria/Quality Elements	1-Never met	2-Rarely met	3-Sometimes met	4-Often met	5-Always met	Evidence	Total Score
1 Primary/ Basic Level							
The care provider undertakes a basic assessment of the child’s and their family’s psychosocial needs.							
Community support for the child and their family with regards to basic psychosocial needs is promoted and provided for at a basic level.							
Referral systems are in place to ensure that the child and their family’s basic psychosocial needs are met through a network of available services.							
Grand Score							
2. Secondary/ Intermediary Level (All of level 1 plus)							

A comprehensive assessment of the child and their family's psychosocial needs is undertaken, and a plan of action developed to support these							
The identified psychosocial needs of the child are met in an age-appropriate manner, by a professional care provider trained in social care skills for children. Where such care providers do not exist, formal arrangements are made to enable access to such care.							
On behalf of the child and their family, the service facilitates appropriate contacts with other networks within the community, where available, to ensure that the child's needs are met.							
Grand Score							
3. Tertiary/ Specialised Level (All of level 2 plus)							
A children's social care professional is part of the core clinical team and provide services to the child and their family to address complex psychosocial needs.							
Training and mentorship in the psychosocial needs of children and their families is provided to level 1 and 2 service providers, as appropriate.							
Information is available on existing community-based social support networks where the child and their family can access care beyond that of the specialised organisation.							

There is a well-documented process for receiving and managing referrals from level 1 and 2 service providers and other organisations, in order to meet the psychosocial needs of the child and their family.							
The service provider undertakes a leadership role with regards to psychosocial care for children and their families, including documentation of best practice and research.							
Grand Score							

Standard 3.4: End-of-life care in children

Standard Criteria/Quality Elements	1-Never met	2-Rarely met	3-Sometimes met	4-Often met	5-Always met		
1 Primary/ Basic Level							
Basic support for the dying child and their family is provided within their home setting.							
Provision is made to enable the child and their family to participate in customary or religious end- of-life rituals that have meaning for them.							
Basic spiritual and social support is provided by the community to the child and their family.							
The child's primary care giver is supported in their role							
There is a close working relationship with level 2 and 3 service providers to ensure that the child dies in peace and dignity.							

Grand Score							
2. Secondary/ Intermediary Level (All of level 1 plus)							

Symptoms in the dying child are assessed and documented.							
Treatment and care is based on the wishes of the child and their family.							
The child and the family are given information about the signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances.							
End-of-life issues and the anticipation of the death of the child are honestly discussed with the child and their family in a socially and culturally appropriate manner.							
Immediately following the death of the child and during the early bereavement phase, families and caregivers are given time and support to help with adjustment to the death of the child.							
There is a close working relationship with level 1and 3 service providers to ensure that the child dies in peace and dignity.							
Grand Score							
3. Tertiary/ Specialised Level (All of level 2 plus)							
Specialised advice is available for care providers on managing challenging symptoms and situations when caring for a dying child.							

A close working relationship is maintained with level 1 and 2 service providers to ensure that the child dies in peace and dignity.							
There is a well-documented referral process for ensuring the continuity of care for the dying child, wherever they may be cared for, and support is given to level 1 and 2 service providers as needed.							
Guidance and support are available to any care provider who needs advice about ethical dilemmas related to end-of-life care and decision making.							
Debriefing is available for caregivers who need support following the death of a child who they have been caring for.							
The service takes a lead on establishing good practice in care for the dying child and their family, and teaches others how to care for the dying child.							
Grand Score							

Standard 3.5: Bereavement Care for Children

Standard Criteria/Quality Elements	1-Never met	2-Rarely met	3-Sometimes met	4-Often met	5-Always met		
1 Primary/ Basic Level							
Information about loss and grief and the availability of bereavement support is made available to the child's family before and after the death of the child, and to children before and after the death of a parent.							
Information about completing bereavement tools, e.g. memory books or boxes, is provided to families prior to the death of a family member, and support given to use these.							
Basic assessment is undertaken on how well the family is coping with regards to the death of a child and referral made for more intense support as required.							
Basic assessment is undertaken on how well children are coping with regards to the death of a parent and referral made for more intense support.							
Grand Score							
2. Secondary/ Intermediary Level (All of level 1 plus)							
Good referral and support systems are in place between level 1, 2 and 3 service providers so that emotional and bereavement support for children can be provided to those who need it.							

3. Tertiary/ Specialised Level (All of level 2 plus)							
Guidelines are developed and available for providing bereavement support to children and their families.							
Professional care providers trained in bereavement support for children are available to support those with complex bereavement needs and to support care providers from level 1 and 2 service providers.							
A healthcare professional trained in bereavement support for children co-ordinates the bereavement support programme for children.							
Education about loss, grief and bereavement in children is provided for staff and volunteers of level1, 2 and 3 service providers.							
Grand Score							

Standard 3.6: Ethical care, human rights and legal support for children

Standard Criteria/Quality Elements	1-Never met	2-Rarely met	3-Sometimes met	4-Often met	5-Always met	Evidence	Total Score
1 Primary/ Basic Level							
All care providers should know and understand the rights of the child and their family, along with their organization’s responsibilities as identified in laws, charters and regulations.							

Care providers should work collaboratively with the community served in order to effectively protect and advance the rights of the child.							
The rights of the child and their family are made known to them in a language and form that they can understand.							
When the child is unable to understand his or her rights, a mechanism is put in place to ensure that his or her carers are included in the process of protecting those rights.							
The child and their family are enabled to participate in care decisions through the provision of basic information regarding the care and treatment proposed.							
Support is provided to the child and their family to protect their rights to participate in the care process.							
There is a process in place to identify and respect the values and beliefs of the child and their family.							
Information on alternative care services is provided when the service provider cannot provide the care or services needed							
Grand Score							
2. Secondary/ Intermediary Level (All of level 1 plus)							
When the child is below the age of consent, consent is provided by the family and, where possible, assent from the child.							

The name of the legal guardian is recorded in the patient care file.							
Grand Score							
3. Tertiary/ Specialised Level (All of level 2 plus)							
The service provider has a clearly defined consent process described in policies and procedures which can be shared with level 1 and 2 service providers as appropriate.							
Advice is provided to level 1 and 2 service providers on the legal and ethical rights of the child and how these can be implemented in palliative							
Grand Score							