

Caprice Knapp · Vanessa Madden
Susan Fowler-Kerry *Editors*

Pediatric Palliative Care: Global Perspectives

 Springer

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Foreword by Dr. Kathleen M. Foley

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ISBN 978-94-007-2569-0

e-ISBN 978-94-007-2570-6

DOI 10.1007/978-94-007-2570-6

Springer Dordrecht Heidelberg London New York

Library of Congress Control Number: 2011942747

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Printed on acid-free paper

Springer is part of Springer Science+Business Media (www.springer.com)

Foreword

Much progress has occurred in the development of pediatric palliative care globally over the last 15 years. Yet, much more needs to be done to address the growing number of children who could benefit from such care. Estimates of the need for palliative care for children globally vary, but upwards of seven million children are in need of palliative care services today.

There is now wide acceptance that palliative care is a serious public health issue with increasing attention by governments to integrate palliative care into their national health strategies to address the growing numbers of adults and children who require such care.

Palliative care is also now recognized as a human rights issue and patients and families have a “right to health,” or a right to receive such care. Various human rights declarations refer to this right to palliative care and a governments’ obligation to provide such services and essential medicines.

The World Health Organization (WHO), when it published its monograph on Cancer Pain Relief and Palliative Care for Children in 1996, intentionally set forth a definition for pediatric palliative care that attempted to be both comprehensive and inclusive to address the needs of children with life-limiting illnesses.

The WHO defined pediatric palliative care as the active total care of the child’s body, mind and spirit. Health care providers must evaluate and alleviate a child’s physical, psychological and social distress. The definition emphasizes that palliative care begins at the time of diagnosis and continues regardless of whether or not a child receives disease directed treatment. Such care encompasses a broad, multidisciplinary approach that includes both the family and the community and is provided in a range of settings from hospital, to clinic, to home and implemented even if resources are limited.

This unique and timely book captures the progress and vision of many dedicated groups around the world who have worked to advocate for and develop palliative care services for children. Each of the book chapters describes the efforts and the challenges leaders in countries are experiencing as they address the palliative care needs of children with life-limiting illnesses. Each country specific chapter details the current state of pediatric care services and demonstrates how early initiatives in palliative care and varied approaches have led to the development of a range of

services from pediatric hospices to hospital-based palliative care units and teams to community and home-based care services, all adapted to the needs and resources of each country.

Such programs range from sophisticated academic clinical and research and educational programs to more community and home-based models of care; they also vary in their educational, service and research roles and in the size and capacity of the services they deliver. The services provided vary depending on the disease entities of the children and the setting in which care is delivered (e.g., cancer, HIV/AIDS, neurodegenerative diseases etc.) but all describe an impressive degree of professionalism with integration of clear standards to provide basic palliative care. Yet, all encompass in their everyday activities, the WHO definition and philosophy of pediatric palliative care with a focus on the quality of living of the patient and family as the unit of care.

As each country describes its challenges and barriers to become fully integration and receive acceptance of pediatric palliative care, common barriers emerge that seem universal. These include: the lack of health care professional knowledge, education and training in palliative care; the lack of essential medicines for pain and symptom management; the lack of communication among healthcare professionals and patients and families; the lack of resources, both financial and social, to support such care; the lack of priority given to palliative care by the common disease entities afflicting children, e.g., cancer and HIV/AIDS; and finally, the lack of research to guide evidenced-based approaches to care.

This compendium of information on pediatric palliative care services globally serves as a rich resource of information on the developmental efforts to advance pediatric services. All three editors are internationally recognized as leaders in pediatric palliative care and they themselves have contributed significantly to the field's growth and development. They bring their own advocacy and support to the field building of palliative care for children through the organization of the content of the text and the broad array of countries represented. In particular, they have provided a framework for capturing the growth of the field of pediatric palliative care that respects and represents the critical importance of context and setting, culture and resources.

This book is a major contribution to the process of documenting the development of pediatric palliative care and a tribute to those individuals and teams with the vision and commitment to advance pediatric palliative care. Children worldwide deserve nothing less.

Dr. Kathleen M. Foley

Acknowledgements

The idea for this book was born at an altitude of 30,000 feet. In 2005 I accepted a position at the University of Florida in the College of Medicine. My first assignment was to conduct research and evaluation of a new integrated pediatric palliative care program in Florida. I had no idea what that meant and as I began to browse the literature, I was surprised how little information existed. Specifically, I had a difficult time finding about how these programs were developed, implemented, and operated. After a few months of searching I decided to head to London which seemed to be the birthplace of palliative care. My 9-month old daughter, my mother, and a co-worker and friend Pam Simmons joined me on this trip. We had a great time visiting children's hospices in England and Scotland and I learned a lot about how care was delivered, to whom, and the barriers that the hospices faced. Sitting on the airplane on the way home however, it struck me how lucky I was to have the resources to make that trip and how it was unfortunate that if I was unable to find this information neither would others. Since that time, I have learned so much about pediatric palliative care from my experiences with Florida's Partners in Care: Together for Kids program and reading everything I could get my hands on. Betsy Shenkman, Phyllis Sloyer, and Charlotte Curtis provided excellent guidance and mentorship. As a result, our team was able to publish many peer-reviewed papers and make valuable contacts in the pediatric palliative care community. Yet, I just could not get rid of that nagging feeling that the experiences and stories of many in the pediatric palliative care community were untold. I am thankful that Springer gave us the opportunity in 2010 to tell those stories.

Of course, we would have no book without the exceptional contributions of each and every author. Thank you all. The countless families and children who have been the inspiration for, and the recipients of, pediatric palliative care programs around the world are the reason that this book exists. *Behold, children are a heritage from the Lord- Psalm 127:3.*

Special thanks to Vanessa Madden and Susan Fowler-Kerry who agreed to go on this journey with me despite being incredibly busy in their own lives; I am blessed by their help and friendship. Lindsey Woodworth deserves many thanks for organizing this project and her superb attention to detail. My family has been my greatest inspiration and support throughout this process. My parents, Charles and Sherry

Garing, encouraged me and were always willing to help care for my daughter when I was faced with a deadline. Moorea, my beautiful daughter, turned four during the writing of this book and learned that she would be a big sister! Finally, my husband Colin provided plenty of love, support, patience, and humor.

Caprice Knapp

In the fall of 2006 I had the opportunity to move to the United States to take a research position at the University of Florida. As an Australian living and working in the U.S., I was struck by how health care systems profoundly impact the way in which care is delivered at the local, state, and national levels. It is with this in mind that I would like to thank all the contributing authors for giving us a global perspective of pediatric palliative care. In each country pediatric palliative care is marching forwards, sometimes in situations where resources are scarce and the challenges immense, because of the commitment of health care providers, hospices, hospitals, advocates, policy makers, and researchers alike. We hope that this book is a useful resource for people who wish to further develop and promote pediatric palliative care in their own countries. The authors have provided valuable information on how pediatric palliative care operates under funding and resource constraints and the excellent local initiatives that are emerging and thriving.

I would also like to thank everyone involved with Florida's Partners in Care: Together for Kids program (PIC:TFK). This demonstration program is one of the first programs nationally to allow publicly-insured children to receive palliative care alongside curative or life-prolonging therapies. For all that I have learnt and continue to learn from PIC:TFK, I would like to thank Children's Medical Services Network, the Agency for Health Care Administration, the hospices, and most importantly the families. The wellbeing of children and their families is at the heart of pediatric palliative care, and I am constantly humbled by the courage and strength of the children and their families and the dedication of those who care for them. On a personal note I would like to thank Dr. Knapp, Dr. Fowler-Kerry, Dr. Sloyer, Dr. Shenkman, and Charlotte Curtis for their contributions to my research career; and Lindsey Woodworth and Deborah Rapalo for their invaluable assistance.

Vanessa Madden

Conventional terms of acknowledgement cannot begin to reflect the contributions of our global authors to this book. Your commitment and passion to improve the lives of countless numbers of children world-wide with palliative care needs and their families was evident and clearly articulated through each of your chapters. A consistent theme though out was that, "you have all decided to be a rainbow in someone's cloud". The result is the creation of a text where we can find new solutions together.

The process of editing a book can be nothing short of a daunting task but I must confess that working with both Caprice and Vanessa has been an amazing journey. So many thanks to you both for the privilege of working with you.

A special thanks always to my mom and dad, Art and Hazel Fowler, I am so lucky to have parents like you. Joel, my husband, you are a constant support and have cooked more than your share of dinners. To my two beautiful daughters, I love you both and I hope that I have given you the inspiration to go after your dreams and desires. Throughout the work on this book, I often thought often about how fortunate and blessed I am to have two healthy children.

Susan Fowler-Kerry

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Abbreviations

AAP	American Academy of Pediatrics
ACH	Association for Children's Hospices
ACT	Association for Children with Life-Threatening or Terminal Conditions and Their Families
AIC	Agency for Integrated Care
AIDS	Acquired Immune Deficiency Disease Syndrome
ALCP	Latin-American Association of Palliative Care
APC&PCA	Armenian Pain Control and Palliative Care Association
APCA	African Palliative Care Association
APPM	Association for Paediatric Palliative Medicine
ARI	Acute Respiratory Infection
ART	Anti-retroviral Therapy
BCH	Belarusian Children's Hospice
BiPAP	Bilevel Positive Airway Pressure
BSc	Bachelor of Science
BSPPM	British Society for Paediatric Palliative Medicine
CAM	Complimentary Alternative Medicine
CAMHS	Child and Adolescent Mental Health Service
CANICA	Centro de Atencion al Nino con Cancer
CCCL	Children's Cancer Center of Lebanon
CCF	Children's Cancer Foundation
CCH	Children's Cancer Hospital
CCHE	Children's Cancer Hospital Egypt
CCN	Community Children's Nurse
CCOPMM	Consultative Council on Obstetric and Paediatric Mortality and Morbidity
CENDEISS	Teaching and Research Center of the Costa Rican Social Security
CHD	Congenital Heart Disease
CHI	Children's Hospice International
ChiPPS	Children's Project on Palliative/Hospice Services
CHOC	Childhood Cancer Foundation
CHPCA	Canadian Hospice Palliative Care Association

CIHR	Canadian Institutes for Health Research
CKD	Chronic Kidney Disease
CNPCC	Canadian Network of Palliative Care for Children
CNPH	Canadian Network of Pediatric Hospices
CPAP	Continuous Positive Airway Pressure
CPIP	Clinical Practice Improvement Project
CPL	Centre of Palliative Learning
CSAC	College Specialist Advisory Committee
CUBE	Caring, Understanding, Believing, Empowering
DCPC	Daniel's Care Palliative Care
DDHS	District Director of Health Services
DHB	District Health Board
DME	Durable Medical Equipment
DNRO	Do Not Resuscitate Order
DPOWMF	Diana Princess of Wales Memorial Fund
DRI	Drug Relief International
EAPC	European Association of Palliative Care
ECEPT	Eastern and Central Europe Palliative Care Task Force
EDC	Education Development Center
EFPPEC	Educating Future Physicians in Palliative and End-of-Life Care
ELNEC	End-of-Life Nursing Education Consortium
EOL	End of Life
EU	European Union
FBO	Faith Based Organisation
FONASA	National Health Fund
GDP	Gross Domestic Product
GP	General Practitioner
HAU	Hospice Africa Uganda
HBC	Home Based Care
HIV	Human Immune Virus
HIV	Human Immunodeficiency Virus
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
HOB	Hospice of the Bluegrass
HOSPAZ	Hospice and Palliative Care Association of Zimbabwe
HPCA	Hospice Palliative Care Association
HPN	Hospital Provincial Neuquen
HSE	Health Service Executive
HSSP	National Health Sector Strategic Plan
IAHPC	International Association of Hospice and Palliative Care
ICAH	Institute of Child and Adolescent Health
ICCPO	International Confederation of Childhood Cancer Parent Organizations
ICD	International Classification of Diseases
ICPCN	International Children's Palliative Care Network

IHS	Island Hospice and Bereavement Service
IMCh	Institute of Mother and Child
IMCI	Integrated Management of Childhood Illnesses
IMF	International Monetary Fund
IMPACT	Guidelines for Pain Management Issued by the European Association for Palliative Care
IMR	Infant Mortality Rate
IPPC	Initiative for Pediatric Palliative Care
ISM&H	Indian System of Medicine and Homeopathy
JMC	Joint Medical Clinic
KFSHRC-R	King Faisal Specialist Hospital & Research Centre – Riyadh
KHCC	King Hussein Cancer Center
KKH	KK Women’s and Children’s Hospital
km	Kilometre
LHC	Lodz Hospice for Children
LLC	Life-Limiting Condition
LLD	Life Limiting Disease
LLI	Life Limiting Illness
LOL	Laugh Out Loud
LPHC	“The Little Prince” Hospice for Children
LRA	Lord’s Resistance Army
MAP	Membership Assistance Programme
MDG	Millennium Development Goal
MECC	Middle East Cancer Consortium
MEDICHI	A Degree in Palliative Care Oncology Offered Through the Digital Learning Network
MOH	Ministry of Health
MOHCW	Ministry of Health and Child Welfare
MPS	Mucopolysaccharidosis
MSW	Medical Social Worker
NACO	National AIDS Control Organization
NANEAS	Multidisciplinary Committee in Charge of Organizing the Care of Children and Adolescents with Special Health Needs
NATO	Northern Atlantic Treaty Organisation
NCI	National Cancer Institute
NCL	Neuronal Ceroid Lipofuscinosis
NFHS	National Family Health Survey
NGO	Non-governmental Organization
NHF	National Health Fund
NHPCO	National Hospice and Palliative Care Organization
NHS	National Health Service
NICE	National Institute of Clinical Excellence
NICU	Neonatal Intensive Care Unit
NMR	Neonatal Mortality Rate
NNPC	Neighbourhood Network of Palliative Care

NSAP	National Standards Assessment Program
NZ	New Zealand
OE	Open Enrollment
OECD	Organization for Economic Co-operation and Development
OPD	Outpatient Department
OSI	Open Society Institute
OSI-NY	Open Society Institute, New York
OVC	Orphans and Vulnerable Children
PACC	Program for All-Inclusive Care for Children and Their Families
PBCR	Population-Based Cancer Registry
PC	Palliative Care
PCAU	Palliative Care Association of Uganda
PCS	Palliative Care Services
PCT	Primary Care Trusts
PCU	Palliative Care Unit
PCWG	Palliative Care Working Group
PedPalNET	New Emerging Team: Transitions in Pediatric Palliative and End of Life Care
PEOL	Pediatric Palliative and End-of-Life
PEPFAR	President's Emergency Fund for AIDS Relief
PHC	Primary Health Care
PHO	Primary Health Organization
PIC:TFK	Partners in Care: Together for Kids
PICU	Paediatric Intensive Care Unit
PINDA	National Child Antineoplastic Drugs Program (“Programa Nacional Infantil de Drogas Antineoplásicas”)
PLWHA	People living with HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission
POON	Paediatric Oncology Outreach Nurse
PPC	Paediatric Palliative Care
PPCPCC	Pediatric Palliative Care and Pain Control Clinic
PPCU	Pediatric Palliative Care Unit
PPM	Paediatric Palliative Medicine
PPOS	Paediatric Palliative Outcome Scale
PR and PC	Pain Relief and Palliative Care
PS	Performance Status
PSNZ	Paediatric Society of New Zealand
QoD	Quality of Death
RCGP	Royal College of General Practice
RCH	Royal Children's Hospital
RCN	Royal College of Nursing
RCPCH	Royal College of Paediatrics and Child Health
RCPH	Royal College of Paediatric and Health Care in London
SAPP	Specialised Out-Patient Paediatric Palliative Care
SCCS	Sarawak Children Cancer Society

SCD	Sickle Cell Disease
SGB V	Sozialgesetzbuch Fünftes Buch
SGB XI	Sozialgesetzbuch Elftes Buch
SHA	Strategic Health Authorities
SickKids	Hospital for Sick Children, Toronto
SIG	Special Interest Group
SMA-1	Spinal Muscular Atrophy Type 1
SSA	Sub-Saharan Africa
TB	Tuberculosis
TPOG	Turkish Pediatric Oncology Group
TRAC-PG	Team for Research with Adolescents and Children in Palliation and Grief
U5 MR	Under Five Year Mortality Rate
UK	United Kingdom
UN	United Nations
USD	United States Dollar
VPPCP	Victorian Paediatric Palliative Care Program
VSK	Very Special Kids
WHC	Warsaw Hospice for Children
WHO	World Health Organisation
WTO	World Trade Organization

Part I

Overview

Chapter 1

An Overview of Pediatric Palliative Care

Caprice Knapp, Vanessa Madden, Lindsey Woodworth,
and Susan Fowler-Kerry

Abstract Palliative care has long been a model of care that focuses on both patients with life-limiting illnesses and their family members. This is especially true in pediatrics where parents, siblings, grandparents and others are affected by a child's illness. Yet, provision of pediatric palliative care around the world is scant. There are of course many reasons for this such as finances, lack of trained professionals, and a lack of general awareness by the public or policymakers. Despite these barriers, and many others, many countries have found ways to provide this care and those countries are both resource-rich and resource-poor. It is important for these countries to share their stories, which include valuable information on how barriers were overcome and programs were developed and implemented. Only through information dissemination will countries with no programs be able to learn from others and to identify strategies that they can use to help advance the pediatric palliative care movement worldwide.

Keywords Pediatric · Palliative care · Hospice · International · Comparisons · Barriers · Enablers · Provision · Development · Strategies · End of life

1.1 Introduction

Every day children around the world die. They die from a variety of causes such as malnutrition, accidents, complications of birth, AIDS, and cancer. No matter what the causes or circumstances, a child's death always results in heartache, grief, and suffering for families and communities. Yet, there are a league of professionals whose sole mission it is to ease the hardships of these children at the end of life and to support family members through the grieving process. Countless doctors, nurses, social workers, psychologists, and advocates around the world work tirelessly to ensure that children and families receive the best care possible under these difficult circumstances. These committed individuals from multiple disciplines have

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found a unifying bond in the field of pediatric palliative care. Born out of the modern day hospice movement of the 1960s, pediatric palliative care strives to care for children in a holistic manner. Not only are the children's physical, emotional, and spiritual well-being of primary concern to these multidisciplinary teams, their families' needs are considered just as important. Mothers, fathers, siblings, and grandparents just to name a few are also cared for by the team. As such, palliative care, and more importantly pediatric palliative care, is unique in the healthcare arena. Oftentimes healthcare is solely focused on a cure and providers are trained to diagnose, treat, and manage symptoms. Unfortunately, many patients have uncertain prognoses. Even the most skilled healthcare workers do not always know whether a treatment will be effective or if ultimately a cure will be found. When these uncertainties manifest themselves in inconceivable outcomes, such as a child transitioning to a terminal stage of illness, pediatric palliative care can be a light in an otherwise dark world.

If pediatric palliative care, which is based on providing holistic support to the child and family, is such a laudable model of care then why is care not always available to all children? Should all children have access to programs in the area they live, and should these programs take into account their unique culture and environment? Children's Hospice International has estimated that each year nearly 7 million children around the world could benefit from pediatric palliative care worldwide [1]. And while statistics of those who do receive care around the world are not readily available, it is widely understood that access to pediatric palliative care is limited. In a 2011 study, Knapp and colleagues conducted a systematic review of 117 published and unpublished resources on the provision of pediatric palliative care [2]. Using established definitions developed by the International Observatory for End of Life Care, the study classified all countries recognized by the United Nations into four levels of pediatric palliative care provision. Levels are ascending in nature whereby Level 1 indicates no known pediatric palliative care activities and Level 4 indicates multiple provision and integration with mainstream service providers. Results from the study suggest that 65.6% of countries around the world were at Level 1; 18.8% at Level 2; 9.9% at Level 3; and, 5.7% at Level 4. Not only was the lack of provision an important finding of the study, lack of information was also commonplace. For countries with no provision and scarce resources to develop a program, it is important to have an understanding of other countries' experiences. By learning from each other, the international community has an opportunity to leverage their experiences and advance pediatric palliative care.

Dissemination of information is always costly and lack of information can lead to inefficiencies and welfare losses in a society. A fundamental assumption of information dissemination models is that early adopters are willing to take risks if they expect increased returns on investment or better patient outcomes. Another assumption is that adoption is influenced by the size of one's network. Having a wide circle of colleagues, networking opportunities, friends, and even family are linked to increased information dissemination. In the case of pediatric palliative care these assumptions mean that policymakers and healthcare providers must understand, or even experience firsthand, the benefits to patients and families in order to

consider supporting them. The more quickly that evidence-based information becomes available and disseminated, the faster the cause will advance.

1.2 Book Structure

This book seeks to diffuse information about pediatric palliative care, by allowing countries to tell their own stories, to describe the benefits to patients and families in their own settings, to describe barriers and the strategies used to overcome them, to celebrate triumphs, to recognize pioneers in their field, and to describe a roadmap for the future. Oftentimes pediatric palliative care texts include one chapter on international experiences, making it difficult to describe an array of experiences or allow for in-depth explanations. The countries described in this book have diverse health-care systems, geopolitical climates, levels of human development, and economic conditions. Yet, common themes abound. Countries face common barriers such as funding, education and training of providers, acceptance of palliative care by patients and families, and problems in forming organizations to advance the pediatric palliative care movement. Although there is an underlying theme of barriers throughout the chapters, there is also a common thread of persistence and success. The tenacity of the pediatric palliative care community is demonstrated in countries where several of these barriers have been conquered. Successful development and implementation of pediatric palliative care programs in resource-poor countries provides hope to those in similar circumstances. Moreover, successful integration of palliative care into the wider healthcare system in resource-rich countries demonstrates how even the most advanced societies can continue to push the boundaries of pediatric palliative care.

1.3 Chapter Highlights

Readers are encouraged to, and will want to, read the entire book to grasp the full range of countries' experiences. However, the following information provides a few highlights of each chapter.

1.3.1 Africa

1.3.1.1 Malawi

In all of the African chapters, it cannot be denied that the HIV/AIDS pandemic has played a role in shaping pediatric palliative care. The high rates of infection have been well-documented as well as some reasons for why they persist (e.g., migration patterns due to job seeking, lack of education, etc.). Children in Malawi are especially affected by the pandemic as they may become infected themselves, or they may have lost one or both of their parents. As a result of these trends, and inspired by

a visit from Dr. Annie Merriman, three sites in Malawi developed pediatric palliative care programs.

1.3.1.2 South Africa

South Africa is a superb example of how a resource-poor country can be successful in building and sustaining a national pediatric palliative care agenda. As in other African countries, poverty and HIV/AIDS have had perhaps the greatest impact on the need for pediatric palliative care. Politics and non-governmental organizations have also played a significant role. For the past 30 years hospices, both adult and pediatric, have been providing palliative care to children. Pediatric-specific facilities started in 1992 with Bloemfontein Children's Hospice and by 2010 there were 60 children's programs in South Africa. Not only are the numbers of facilities impressive, but advocates and members of the medical community have played a significant role in spreading pediatric palliative care to other African countries through the Hospice Palliative Care Association of South Africa and the African Palliative Care Association and sharing their experiences internationally through the International Children's Palliative Care Network and the World Health Organization to name a few organizations.

1.3.1.3 Uganda

Uganda has a low Gross Domestic Product (GDP) and high poverty rates. As a result of this and political turmoil, it has been difficult for the country to meet the health-care demands of its citizens. Recent healthcare policies are focused on public health and building infrastructure. For example, the recent 2010 National Development Plan was focused on health promotion, disease prevention, and early diagnosis and treatment of diseases. With such an emphasis on the provision of basic healthcare needs and services, it is impressive that pediatric palliative care has developed over time. Programs include independent services (such as Mildmay Uganda), inpatient services (such as those at Mulago Hospital), and home-based services. Although experts recognize the work that lies ahead, much has been accomplished in Uganda to care for children with life-limiting illnesses.

1.3.1.4 Zimbabwe

The palliative care experience in Zimbabwe can be characterized by ups and downs. As GDP has fallen and risen over recent years, and with it levels of poverty, palliative care has been affected through the labor supply and funding. Yet, movement towards more palliative care for children has been steady. Palliative care was incorporated into the national Cancer Control Strategy, the children's oncology ward at Parirenyatwa Hospital, and Island Hospice and Bereavement Service for example. Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) has played a significant role in pediatric palliative care. HOSPAZ works to set standards of care, increase capacity, as well as advocating for and coordinating palliative care in

Zimbabwe. One of the major accomplishments of HOSPAZ, along with UNICEF, was to train about 60 partners in pediatric palliative care and antiretroviral therapy adherence.

1.3.2 Asia

1.3.2.1 Armenia

Armenia is a young country having gained independence in 1991. However, the gain in independence was met by an economic crisis and emigration. Rebuilding the economy and the healthcare system has been slow, but steady. By 2006, Armenia spent just under 2% of its GDP on healthcare. Palliative care is a relatively new concept to Armenians having established a national organization devoted to the topic in 2003. Five years later several experts began to recognize the need in pediatrics, especially for children with cancer. Not only is this model of care new for the medical community, recent reports note that only 13% of parents in Armenia have even heard of palliative care. Though no formal pediatric programs exist, there are several pediatric services that provide some of the components of palliative care.

1.3.2.2 India

India is one of the most populated countries in the world with about 1.15 billion people. Indian citizens are as diverse as they are numerous. With over 30 different recognized dialects and 28 states, India is truly an interesting and complex country. Pediatric palliative care is ripe for advancement in India with high levels of poverty and low levels of spending on healthcare and public health programs. Palliative care began to become recognized in the 1980s, but the same cannot be said for pediatric palliative care. Innovative programs in Kerala, Mumbai, Delhi, and Hyderabad have been developed. These programs provide information and support to a national pediatric palliative care agenda in its infancy.

1.3.2.3 Malaysia

A multi-ethnic country in Southeast Asia, Malaysia has a low infant mortality rate and a long life expectancy as compared to other countries in the region. Malays spend 4.4% of their GDP on healthcare, which is provided by the government and private sector. As in most countries, adult palliative care was developed first and that began in the early 1990s. Pediatric palliative care only recently has been recognized as a subspecialty in pediatrics and the uptake of this training has been limited. Much of the current work in Malaysia is focused on introducing the topic to pediatricians and making them more familiar with the field. Currently, 10 of the 18 community-based palliative care programs accept pediatric patients. Other pioneering programs include Malacca General Hospital and Hospice Malaysia.

1.3.2.4 Middle East

The Middle East Cancer Consortium was developed in 1996 with the goal of promoting palliative care services for adults and children. By combining the skills and expertise of regional members, the Consortium was able to conduct surveys of baseline information and perceived barriers to pediatric palliative care. Results from the surveys were used to develop standards of care and to build consensus among the group as how best to proceed. As the group builds on this momentum they are faced with unique challenges. Religion, culture, and tradition play significant roles in the Middle East and each of these must be considered when training medical personnel and talking to families whose children have life-limiting illnesses.

1.3.2.5 Saudi Arabia

Located in the Arabian Peninsula, Saudi Arabia is home to more than 27 million people and has some of the largest oil reserves in the world. A society steeped in the Islamic faith, Saudi Arabians access both modern and traditional health-care in some areas of the country. Palliative care efforts began in the King Faisal Specialist Hospital and Research Center in Riyadh in 1991. Patients from neighboring countries also have access to this comprehensive and unique program. Growth in palliative care has to this point been concentrated in tertiary medical centers in large cities and there are now about 20 trained palliative care physicians. To date, no formal pediatric palliative care programs exist. However, a few pediatric oncologist/hematologists are pursuing sub-specialty training. Saudi Arabia is in the beginning stages of developing pediatric palliative care. However, there is interest in improving awareness, improving access, and building consensus. It will be interesting to see how the plans unfold and eventually become realities.

1.3.2.6 Singapore

Singapore is an island in Southeast Asia. The country has a high GDP and an expensive cost of living. Although the health sector is well organized, it primarily funds inpatient care, resulting in a barrier for establishing pediatric palliative care programs outside of the hospital walls. In 2004, the first children's program was started at KK Women's and Children's Hospital. Children with cancer were the first focus, but one-year later the scope of services were extended to treat non-cancer cases. This well-established program has allowed for training of staff, a bereavement support group in the neonatology department, and a homecare program.

1.3.2.7 Thailand

Although the Thai government has a universal healthcare system, palliative care is not a current priority to receive funding. Yet, the demand for pediatric palliative care exists and any guidelines that exist to meet these demands are typically facility based (in academic, tertiary hospitals). There are functioning pediatric palliative