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Les soins palliatifs ne sont pas un luxe mais un droit de l'homme et un élément essentiel d'une couverture sanitaire universelle (CSU)

New Approaches to Expanding Palliative Care in the Caribbean Trouble in Paradise?

De Dingle Spence, Brittany Bromfield and Steven Smith

Recognition of the enormous need to incorporate palliative and end of life care into usual medical care has given rise, over the years, to small oases of palliative care, usually domiciliary based, and provided by NGOs or faith-based organizations. Unfortunately, these important services are often inaccessible to wider populations, often for reasons of geography, high transport costs for patients to access care and insufficient capacity of the care providers to match what is a huge unmet need (Spence et al., 2018). So, although the concept of hospice and palliative care is not unfamiliar in the Caribbean, new momentum has been gathering over the past five years and we are now entering an exciting phase where the hard work and persistent advocacy by individuals and small organizations is finally paying off. In this article we share some of the recent advances in hospice and palliative care provision in the Caribbean region.



Dr. Dingle Spence with a patient at the Hope Institute Hospital (2020).
Photo: © Steven Smith

The Caribbean is a region of the Americas that consists of the Caribbean Sea and its islands and also includes some mainland countries which share the Caribbean coastline. When most of us think about the islands of the Caribbean we think of the proverbial sun, sea and sand, coconut palms and the beauty of perpetual blue skies. What we may not know is that when it comes to health and healthcare, Jamaica, Barbados and Trinidad and Tobago have some of the highest mortality rates from cardiovascular disease in the Americas, and cancer is the second leading cause of death across the region (Cayon, 2020). For the purposes of this article we refer to the Caribbean region as including those nations who are members of, or who have observer status in the Caribbean Community (CARICOM).

Under resourced public health care systems

Although these small island nations may share a geographic region and a common history of colonialization, there are a multiplicity of different cultures, languages and socioeconomic and political perspectives in the region. The Caribbean comprises of English, Spanish, French and Dutch speaking peoples with French creole and Jamaican patois now recognized as distinct languages. Many

Caribbean nations have small, open, often fragile economies, heavily dependent on tourism, subject to natural disasters and climate change, and often with under resourced public healthcare systems. Despite the fact that many of these island nations are designated as high-income or upper-middle income countries by the World Bank, (World Development Indicators, 2018), many have rising external debt and inadequate investment in their healthcare infrastructure. The rising incidence and mortality related to cardiovascular disease and cancer is quickly becoming an enormous public health challenge (Razzaghi et al., 2016).

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The resources to provide timely access to cancer care across the continuum of care, and especially for access to palliative care and pain relief, are relatively limited in most Caribbean countries (Spence et al., 2019). Late-stage disease presentations are common, and even when patients do present with earlier stage cancers, trying to navigate access to surgery, chemotherapy, and radiation therapy in under resourced systems can be very difficult for patients, often leading to their unnecessary suffering and untimely death (Cazap et al., 2016). A regional analysis of palliative care development between 2006 and 2011 indicates that no country in the Caribbean had yet to fully integrate palliative care into their health system (Lynch, Connor and Clark, 2013), and this remains the case, even in 2020.

A slow but steady development of palliative care in the Caribbean

There are many interesting stories of the early development of palliative care in the Caribbean. As is often the case, a common commitment to providing relief from pain and suffering at the end of life, brings health care professionals, philanthropic organizations, and business communities together to help develop, often small, not for profit organizations that have historically delivered home based palliative care. For instance, the establishment of the Beacon Foundation in 1986, in Guyana (formerly British Guiana), proved one of the earlier examples of a sustainable and effective domiciliary palliative care service in the Caribbean. The Beacon Foundation continues to provide a domiciliary hospice service, led principally by trained nurses with support from local physicians, and has more recently developed mentoring and training links with St Christopher's Hospice in the UK.

In Jamaica, palliative care, with a focus on cancer pain relief and end of life care was introduced in the early 1980's by a British orthopaedic surgeon who had lived and worked in Jamaica for many years and who later in life developed a keen interest in palliative care. He opened a day hospice in one of the poorer sections of the city, and became one of the first people to successfully advocate for the importation of sustained release morphine tablets into the island.

Prior to this, the only oral formulation of a strong opioid for the relief of severe pain in Jamaica was the "Brompton cocktail", a mixture of low dose morphine, cocaine, alcohol and syrup. Since that time palliative care has developed slowly but steadily in Jamaica. The principal palliative care provider is

now a team based at the Hope Institute Hospital, Jamaica's only dedicated oncology and palliative care unit. The team provides outreach clinics at two other hospitals in the capital city of Kingston. The service is limited to the capital city, and there are still very few community-based palliative care services although almost half of the population lives in rural areas.

The Hope Institute Hospital has recently been invited by the WHO to be part of a global demonstration project which will evaluate different models of palliative care provision across the world's six health regions. In the Cayman Islands, palliative care is well developed and domiciliary hospice care has been provided by a small NGO (Cayman Hospice Care) for nearly 20 years. More recently, the Caymanian business community has helped with the construction of the island's first purpose-built hospice and palliative care unit, known as Jasmine Villa. Barbados has community based palliative care provided by a faith-based organization, and another smaller NGO. In Trinidad and Tobago, palliative care is relatively limited and the existing services are provided by a combination of small public sector, and other not-for-profit entities. In the French Caribbean island of Guadeloupe, Les Soins Palliatifs is provided by PAF- Guadeloupe, an association founded in 2010 dedicated to public education and training of healthcare workers in both the art and the science of providing good palliative care.

Main barriers for adequate palliative care provision

Some of the reasons for continued inadequate palliative care provision in the Caribbean include the lack of a sufficiently trained workforce to deliver the care, (Stoltenberg M et al., 2020; Spence et al., 2018), cultural barriers (Maharaj and Harding, 2016-01-22; Spence et al., 2010), financial constraints, opiophobia and lack of availability of essential medicines (Macpherson C and Aarons D, 2009), and often restrictive government policies.

Two recent initiatives detailed below are aimed at addressing some of these inequities.



JACCRI Palliative Care Training Course at the University of the West Indies (2018). Photo: © UWI

Jamaica Cancer Care and Research Institute (JACCRI): Providing Training in Palliative Care for the Caribbean Region

JACCRI (Jamaica Cancer Care and Research Institute) founded in 2016, is the fruit of a foundational collaboration between the Hope Institute Hospital, the Surgipath and Cytology Laboratory and the University of the West Indies (UWI), Mona – all in Kingston Jamaica - and the Harvard University/Massachusetts General Hospital Centre on Genomics, Vulnerable Populations and Health Disparities. JACCRI is a non-profit organization born of the recognition of the need to provide training and research opportunities for Jamaican health care professionals along the cancer care continuum. JACCRI is keen to engage practitioners in genetics research as one “bookend” on the continuum of cancer care, and at the other “bookend” is palliative care.

As previously mentioned, the provision of palliative care and access to essential medicines for pain relief is severely limited in the Caribbean, and one solution to help change things on the ground is to provide tiered and appropriately tailored training in palliative care medicine to a wide variety of health care professionals.

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JACCRI at work – Dr. Brittany Bromfield at a men's health fair in Kingston, Jamaica. Photo: © Steven Smith

Palliative care training must become part of the medical school curricula

JACCRI is working with the University of the West Indies, the largest university in the Caribbean, to incorporate robust palliative care training into the medical school curricula and to establish palliative medicine as a medical specialty, not only in Jamaica, but in the Caribbean region as a whole. The JACCRI leadership developed and delivered two comprehensive, five day palliative care training programs run firstly in October 2017 and again in November 2018, and used the curricula and expertise of the MGH/Harvard Medical School palliative care program in conjunction with the experience and guidance of leaders in the Caribbean.

The workshops were open to health care practitioners from across the region, and approximately 100 persons from six different Caribbean countries attended. These foundational workshops have served as an introduction for professionals interested in learning the basics of palliative care with the hope that they will continue to expand their knowledge as further opportunities arise. Future projects

include working with the Pan American Health Organization (PAHO) to provide well structured, sustainable training programs in three countries in the region, and working with the UWI to develop diploma and higher level qualifications in palliative care that can be reproduced across the region, and in more than one language.

JACCRI also intends to work with the Ministry of Health and Wellness in Jamaica to encourage the creation of posts within Jamaica's public hospital system for health care professionals with palliative care training. By providing both educational initiatives and employment opportunities in palliative care simultaneously, we may begin to increase our capacity to genuinely deliver this essential public health service to all who need it.



CARIPALCA Website <https://www.caripalca.org/>

CARIPALCA: Regional Collaboration in Palliative Care

In April 2015 the **Hope Institute Hospital** hosted a Caribbean Region Palliative Care Conference which was held at the University of the West Indies (UWI), Mona Campus, Jamaica. With attendees from within the region and from international entities such as the **Pan American Health Organization (PAHO)** and the **International Association for Hospice and Palliative Care (IAHPC)**; the idea of the Caribbean Palliative Care Association (CARIPALCA) was born.

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The concept of creating a regional body emerged. It became clear, however, that there would be much ground work to be done to formalize this entity and to create the strong partnerships required to make it successful.

In October 2016, the IAHP and Barbados Association of Palliative Care held a workshop in Bridgetown, Barbados specifically designed for healthcare professionals interested in improving the availability and rational use of controlled medicines in their own countries. The attendees comprised over 45 health-care professionals and palliative care experts from around the Caribbean who worked together over a two day period to develop individual country action plans to improve the availability and accessibility of essential medicines, especially those for pain relief, and improve access to palliative care for all citizens within CARICOM (Radbruch and De Lima, 2016). This collaborative effort provided the impetus for beginning the formalization of CARIPALCA; driven by the overwhelming support of the attendees at this workshop.

CARIPALCA aims to bring together palliative care communities and interested civil society membership in an effort to further the necessary advocacy, education and policy initiatives across the region. Additionally, it will provide support for national associations to advocate for increased capacity building, research funding, and access to essential medicines. This emergent regional body launched its website (www.caripalca.org) in November 2019. It features educational tools and palliative care resources within a regional context, as well as a growing online directory of palliative care clinical services available throughout the Caribbean. The website also features resource appropriate clinical care guidelines; with its most recent publication providing information to support those caring for palliative care patients with coronavirus.



World Health Organization Demonstration Project Training (March 2020).
Photo: © The Liguanea Club

Palliative care is a critical component of care for all patients facing serious illness and without it, many will die suffering.

Palliative care is a critical component of care for all patients facing serious illness and without it, many will die suffering. In Caribbean communities where significant percentages of the population are poor and where access to good quality healthcare is lacking, providing an essential package of palliative care is critical to help relieve the suffering of many. Training health professionals in palliative care with a focus on primary and community-based care is an essential step forward, especially in our countries where too many people present with late-stage disease, and for whom palliative care and relief of suffering may be the only options available.

JACCRI is collaborating with the Pan American Health Organization (PAHO) to help strengthen Caribbean health systems by delivering regional training courses in palliative medicine in Jamaica in 2021.

A regional organization such as CARIPALCA can serve as a platform for collaboration between countries on many different levels, through the sharing of policies, through pooled purchasing of essential medicines, and through the sharing of expertise across geographical and political boundaries.

A regional organization such as CARIPALCA can serve as a platform for collaboration between countries on many different levels, through the sharing of policies, through pooled purchasing of essential medicines, and through the sharing of expertise across geographical and political boundaries. Hope springs eternal in our small island communities as we continue to improve the provision of palliative care for our collective and individual populations – whilst nurturing our islands' paradise.

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Dr. Dingle Spence, BSc., MBBS, DMRT, Dip. Pall Med, FRCR. Dingle Spence is a Jamaican physician with training in both Clinical Oncology and Palliative Medicine and is the Senior Medical Officer of the Hope Institute Hospital, Jamaica's only dedicated oncology and palliative care unit. She is the director of the Jamaica Cancer Care and Research Institute (JACCRI), a nonprofit organization dedicated to improving cancer care and palliative medicine in the Caribbean. Email

Dr. Brittany Bromfield, MBBS, is a Project Manager for the Jamaica Cancer Care and Research Institute (JACCRI) and a Research Associate for the Harvard/MGH Center on Genomics, Vulnerable Populations, and Health Disparities. Her research interests include developing resource-stratified approaches for palliative care in the Caribbean and improving cancer research and health disparities in lower-middle income countries. Email

Dr. Steven Smith, MBBS, is a Research Associate at the Harvard/MGH Center on Genomics,

Vulnerable Populations, and Health Disparities. He works with the Jamaica Cancer Care and Research Institute (JACCRI) on projects focusing on improving palliative care in low-income and disadvantaged populations. Additionally, he is a member of the Caribbean Palliative Care Association (CARIPALCA) steering committee where he coordinates regional collaborative. Email

Kontakt

Deutschschweiz

Medicus Mundi Schweiz
Murbacherstrasse 34
CH-4056 Basel
Tel. +41 61 383 18 10
info@medicusmundi.ch

Suisse romande

Route de Ferney 150
CP 2100
CH-1211 Genève 2
Tél. +41 22 920 08 08
contact@medicusmundi.ch