

Hospice and Palliation in the English-Speaking Caribbean

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Abstract: This article presents empirical data on the limited availability of hospice and palliative care to the 6 million people of the English-speaking Caribbean. Ten of the 13 nations therein responded to a survey and reported employing a total of 6 hospice or palliative specialists, and having a total of 15 related facilities. The evolving socioeconomic and cultural context in these nations bears on the availability of such care, and on the willingness to report, assess, and prioritize pain, and to prescribe opiates for pain. Socioeconomics and culture also impinge on what medications and modalities of care are routinely available for pain or other conditions and can challenge professionalism, empathy, and responsiveness to patients' unrelieved pain. Although all respondents report having a protocol for pain management, hospice, or end-of-life care, their annual medical use of opiates is well below the global mean. The International Narcotics Control Board (INCB), which monitors such use, encourages Caribbean and other low- and middle-income countries to increase their use of opiates to treat pain, and to overcome both unfounded fears of addiction and overly restrictive interpretation of related laws and regulations. Contextual considerations like those described here are important to the success of policies and capacity-building programs aiming to increase access to hospice and palliation, and perhaps to improving other aspects of health and healthcare. Exploring and responding to the realities of socioeconomic and cultural conditions will enhance public and policy dialogue and improve the design of interventions to increase access to palliative and hospice care. Improving access to palliative and hospice care in the Caribbean demonstrates beneficence and helps to fulfill human rights conventions.

Keywords: Caribbean; pain; palliative care; end-of-life care; socioeconomic and cultural conditions; opiates; policy; beneficence; human rights; professionalism

Introduction

Cancer and other medical conditions cause acute, chronic, moderate, and/or severe pain. Much of this pain is undertreated around the world, despite the growing success and availability of hospice and palliative care.^{1,2,3,4} Hospice and palliative care provide access to safe and effective pain relief, as do pain specialists from various medical backgrounds. Globally, however, many compassionate physicians do not actively treat pain, due to their limited knowledge about related clinical guidelines and evidence, and limited resources.⁵ Access to pain relief is a human right that remains unavailable to many, particularly in low-income settings and low- and middle-income nations.^{6,7,8,9} Even in the United States pain relief is unavailable to many.¹⁰

Globally, access to hospice and/or palliative care tends to be greatest in urban and/or well-funded medical centers. Exposure to such centers generates the erroneous view that the same standard of hospice, palliation, and pain relief is

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equally available everywhere. In reality, hospice, palliation, and pain medicine are practiced differently in different settings, even in wealthy nations, and, in many settings, are not practiced at all.

Similarly, in some settings, moderate and severe pain is not treated aggressively or effectively among patients with chronic or acute conditions. Anecdotes and personal experience indicate that there are doctors who sometimes withhold pain relief to keep a patient conscious and responsive on admission and/or during investigations. It is not clear whether or not this is actually medically necessary for all patients. These doctors typically justify their violation of clinical guidelines for treating pain with opiate medications by claiming that opiates compromise respiration and survival. Although sometimes true for *some* doses and for *some* patients, this is not true for every opiate, dosage, patient, or health condition. Moreover, there are times when the harm of withholding pain relief outweighs the risk of providing it. These times should be determined for each unique patient, and, when possible, with the patient's input.

The uneven access to pain relief in wealthy nations and institutions is exacerbated in other nations and institutions by socioeconomic and cultural conditions. The limited priority and availability of hospice, palliation, and pain relief in middle-income nations is evident in the Caribbean, where socioeconomic conditions limit resources and infrastructure and result in healthcare services and standards that differ markedly from those in wealthy nations.^{11,12,13} Such practical realities restrain the capacity to develop hospice and palliation and to aggressively treat pain. This article provides an update on efforts to engage Caribbean stakeholders in dialogue about hospice, palliation, and pain relief, reported previously in this journal.¹⁴ We present new data on the availability of hospice and palliation in the Caribbean and discuss the evolving Caribbean cultural and socioeconomic context that bears on access to such care. We demonstrate that contextual information is essential to understanding challenges to the provision of palliative and hospice care and pain relief in the Caribbean and suggest that contextual information will enhance efforts to overcome such challenges.

The Study

More than 6 million people live in the 13 English-speaking Caribbean nations that comprise the Caribbean Community (CARICOM), which works to improve regional quality of life.¹⁵ Much pain due to cancer and other common disorders is untreated or undertreated in these nations, and related disease registries and palliative services are rare.^{16,17,18} To document the availability of hospice and palliation in CARICOM nations, we designed a cross-sectional survey of health officials from the 13 CARICOM member nations (Antigua and Barbuda [A&B], the Bahamas, Barbados, Belize, Dominica, Grenada, Guyana, Jamaica, Montserrat, St Kitts and Nevis [SKN], St Lucia, St Vincent and the Grenadines [SVG], and Trinidad and Tobago [T&T]). The one-page survey asked about public and/or private palliative or hospice facilities or specialists, institutional pain protocols, medical access to oral morphine, and related educational activities.

Chief medical officers (CMOs) are the second most senior officials in Caribbean health systems and are knowledgeable about all services provided within their health system; hence CMOs or their designees were recruited by phone and/or email and offered a financial incentive to complete the survey. Contact with CMOs

was initiated through Caribbean colleagues in the region. Some CMOs neither declined nor responded to repeated requests over six months. In these instances, the president of their national medical association was recruited. The descriptive and statistical analyses used were based on the type of data collected. Institutional review board (IRB) approval (#10010) was received from the St George's University IRB in Grenada, which is registered with the Office of Human Research Protections in the United States. Given the nature of the study, and the reality that there are no IRBs in some Caribbean nations, IRB approval was not sought in each of the thirteen nations.

The Findings

Responses from CMOs or national medical association presidents were received from 10 of the 13 CARICOM nations (77%). No response was received from the CMO or medical association president in Dominica, Guyana, or the Bahamas.

Palliative and Hospice Facilities and Specialists

The 10 respondents report a total of 15 hospice or palliative facilities among 8 nations, and a total of 6 hospice or palliative specialists employed among 4 nations. Belize, T&T, SVG, and Jamaica all reportedly have at least 1 facility and employ at least 1 specialist. Both Belize and T&T have 2 private facilities and 2 specialists; SVG has 1 public facility and 3 specialists; Jamaica has 1 public and 1 private facility and 2 specialists; and Montserrat has 1 public facility and 1 specialist. Both A&B and Barbados report 1 public facility and no specialists; SKN reports 1 private facility and no specialists; and Grenada and St Lucia report no facilities or specialists. Additionally, 4 respondents indicated that some form of home care is provided to terminally ill patients.

Pain Protocols and Oral Morphine

Five respondents report having a "protocol for pain management, hospice, or end of life care" (Antigua, Barbados, Belize, St Lucia, and T&T). Of these, only Belize and T&T report having *both* a specialist and facility.

All respondents indicate that oral morphine is medically "available to treat mild or severe pain" but differ in how often their stock is replenished. When asked whether their supply is replenished "monthly, annually, or other," responses included "monthly" (3), "when needed" (2), "quarterly" (1), "yes" (2), and "not sure" (2). Using publicly available secondary data, a positive correlation was found between per capita morphine consumption and male and female patients over age 60 (respectively, $r = 0.972$, $p = 0.0001$, and $r = 0.844$, $p = 0.008$). No correlation was found between per capita morphine consumption and numbers of specialists or facilities.

Education on Palliation or Hospice

Five respondents report that one or more "workshops or educational programs on palliative care" had been held in their nation or health system.

Discussion

This study engaged a group of stakeholders (CMOs and medical association presidents) in thinking about the availability of hospice and palliation in their nations. Their responses confirm the limited availability of hospice and palliative care in the English-speaking Caribbean. Contextual considerations that contribute to, and elucidate, this situation are explored subsequently. Attention to such considerations demonstrates beneficence; helps to fulfill human rights conventions; and will enhance related understanding, dialogue, policy, and interventions that aim to overcome these limitations.

Palliative and Hospice Services and Specialists

The data presented here document the limited availability of hospice and palliation among the 6 million people of the English-speaking Caribbean. The slow response time of participants is typical of Caribbean norms in both professional and social contexts. The numbers of facilities and specialists in each nation cannot be attributed solely to population size or level of industrial development. St Lucia, for example, is larger and wealthier than Grenada but has neither a facility nor a specialist, and although SVG resembles Grenada in population size and industry, it has a facility and several specialists.

Misunderstanding and misinformation about hospice, palliation, and opioids is common in the Caribbean, even among health professionals^{19,20,21} and may contribute to overrepresenting the availability of these services. Such misunderstanding may also help to explain why some nations report having a hospice but no specialist. Many Caribbean health systems host visiting physicians in various specialties, however, so those that do not employ a palliative specialist may sometimes host visitors with that expertise. It is likely that the healthcare professionals at the institutions hosting visiting palliative specialists learn from, and attempt to improve, related aspects of care, but their ability to do so effectively remains hampered by a lack of resources, infrastructure, and expertise.

Some Caribbean patients have difficulty accessing medical care due to disabling conditions or pain, and/or lack of transportation. Confronted with a health system that can do little for them, many terminally ill patients are released from the hospital and/or choose to die at home, where they can be cared for by loved ones, but where they receive little or no pain relief or medical or nursing support.²² In low-income nations, dying at home may offer greater comfort and quality of life than in a hospital.²³ Although not conclusive, anecdotal reports and the data presented here suggest that health services for patients dying at home in the Caribbean are minimal.

Pain Protocols and Opioid Medications

Pain relief is only one component of hospice and palliative care, but it significantly improves the physical and mental health of patients, caregivers, and loved ones. About 80 percent of terminal cancer patients worldwide suffer moderate to severe pain, and 80 percent of these patients have no access to pain medication.²⁴ Early and aggressive pain relief can minimize suffering; reduce time off work; reduce healthcare costs; and improve longevity, physical independence, relationships, sleep, and satisfaction with medical care. The World Health Organization's three-step analgesic

ladder for treating pain is safe, effective, and relatively inexpensive, but many health systems in developing countries are reluctant to adopt it, leaving millions of people to suffer needlessly.²⁵

A 2010 report from the International Narcotics Control Board (INCB) notes that although some countries have reported increases in their use of oral morphine and other opiates to treat pain, these increases are inadequate for effective pain relief in those nations; global medical needs for opiates are not being met, particularly for cancer pain; and impediments to the availability of opiates include the interpretation and administration of related laws and regulations, fear of addiction among professionals and the public, and lack of training about their use.²⁶ That INCB report also calls on governments to examine their methods of assessing medical needs for opiates; to evaluate procedures, laws, and regulations that hinder opiate availability; and to develop policies, guidelines, and professional education to improve the availability of opiates for medical use.²⁷

National per capita consumption of morphine for medical use is a standard measure of undertreated pain, and Caribbean consumption is well below the global mean.^{28,29} Our data do not support the view that having a protocol for pain or end-of-life care is consistent with higher morphine consumption, but our data may reflect respondents' limited understanding and/or implementation of such protocols. Our findings about how often oral morphine is replenished suggest that, as reported elsewhere^{30,31,32} and anecdotally, Caribbean health systems are understocked and sometimes run out.

Opioid analgesics are strictly regulated in the Caribbean, and there is a widespread concern among health professionals about the possibility of addiction to, and misuse and abuse of, opiates. Although in most CARICOM nations oral morphine is sometimes available, it is not reliably available in quantities adequate to relieve cancer pain among their populations. Some of these nations do not consistently provide annual reports on per capita consumption to INCB, and this challenges INCB efforts to monitor, or encourage, its use. These inconsistencies may reflect the limited resources and infrastructure needed to compile and maintain data and/or poor time management in a system that is short staffed. They may also involve political appointments of the ministers of health, CMOs, or chief pharmacists who are responsible for procuring opiates for medical use and reporting annual consumption data to the INCB.

The Caribbean Context

Socioeconomic and cultural influences in the Caribbean bear on the willingness to prescribe opiates and to report, assess, and prioritize pain.^{33,34,35} Although the socioeconomic status in middle-income nations is significantly greater than in low-income nations, it is significantly lower than in wealthy ones, and this affects medical and nursing care and curricula. Socioeconomics impinge on what medications and modalities of care are routinely available, the level and number of staff members per shift or department, the existence of systems to hold staff and administrators accountable for their actions or inactions, the ability to digitize and manage medical records, educational opportunities for staff and administrators, space for confidential discussions with patients, and even the availability of a doctors' lounge. Such working conditions create countless practical and ethical challenges and contribute to burnout; undermine professionalism, compassion, and empathy; impinge on the willingness to believe patient self-reports of pain;

hinder the creation of opportunities for continuing education and professional development; and perpetuate overly restrictive narcotic regulations and misinformation and bias about the medical use of opioids.

Human nature is such that cultural and social norms evolve over time as groups adapt to changing socioeconomic, environmental, and other conditions. Among Caribbean clinicians and patients, the traditional norm is to accept pain as something beyond control. Much of Caribbean culture, social life, and tradition centers around communities of family and church. The inadequate medical response to pain thus contributes to the widely accepted view that pain is God's will. Many Caribbean patients are left with nowhere to turn but traditional bush medicine or herbal remedies, faith, and prayer.^{36,37} The limited availability of palliative and hospice care confronts even Caribbean physicians, nurses, and their families and friends, who also have little choice but to endure untreated or undertreated pain.

Attitudes toward pain among Caribbean physicians are evolving due to their increasing exposure via the Internet and cable television to the expectations of healthcare in North America and Europe; to the standards, communication skills, and work ethic of visiting clinicians; and to occasional opportunities to train in clinical institutions in wealthier nations. Many Caribbean physicians are conversant in bioethics principles including respect for persons, beneficence, and justice, but their ability to apply these principles consistently in patient care is challenged by limitations of resources and infrastructure, and sometimes by related dysfunctional relationships and hierarchies within their health systems.

Even when Caribbean doctors prescribe opiates for hospitalized patients, nurses sometimes withhold them from patients, or wait until the patient shows signs of suffering.^{38,39} One way to overcome such behavior is to reduce related bias and misinformation by incorporating end-of-life issues and guidelines on the use of opiates into medical and nursing curricula.⁴⁰ Online tutorials are part of a successful palliative care intervention in Columbia⁴¹ and may be a useful strategy in the Caribbean and other middle-income nations.

Beneficence

The principle of beneficence requires doctors and other health professionals to comfort patients and to attempt to relieve their pain and suffering. At one time, beneficence was manifested by spending time with patients, listening to them, and holding their hands to offer comfort, reassurance, and maybe even solidarity in our shared human condition. In wealthy nations, spending time with, and comforting, patients is less frequent than it once was, and doctors' focus has shifted to the multitude of new and advanced technologies for diagnosis and treatment. The current trend in the United States seems to encourage doctors to prioritize technology over the art of medicine, which traditionally centered on the way in which doctors demonstrated their knowledge about, and compassion for, each unique patient and the patient's condition and needs. This conception is shifting from the doctor-patient relationship toward the relationship between doctors and technology, and how doctors use technology to improve statistical and/or institutional outcomes rather than patient outcomes.

Based on informal discussion, anecdotes, and observation, it appears that the best Caribbean doctors are well known, respected, and liked by their colleagues and patients in their own nations, and also across the wider Caribbean region.

These doctors demonstrate a strong work ethic and interpersonal skills that enable them to work effectively with teachers, patients, colleagues, and supervisors. In the absence of technologies available elsewhere, they still, today, spend time getting to know their patients and patient concerns, and trying to disclose information to patients in ways that each patient can understand, regardless of socioeconomic or educational background. They are respectful to patients, nurses, and colleagues; concerned with ensuring that patients know how to manage their condition and take prescribed medications; willing to express uncertainty about their diagnoses or management of a patient; and able to maximize the resources available to them for patient care. These exemplary doctors constitute only a small group across the Caribbean. Whereas many of the others work hard and accomplish some of these things, some are sometimes less respectful and communicative than they could be. This may stem in part from working with limited resources and infrastructures, and also from the historic emphasis on paternalism in the Caribbean, developed at a time when there were too few resources to offer patients options and choices about their care. In many situations, this likely benefited some patients, but today, with the growing awareness of bioethics in the Caribbean, paternalism is slowly being replaced with respect for persons. Few Caribbean healthcare institutions, however, have efficient systems for obtaining or evaluating statistics on doctors' performance, patient outcomes, or patient satisfaction; for holding clinicians accountable for their actions or inactions; or for establishing knowledgeable, reliable, and transparent ethics committees.

Conclusions

Bioethics involves the sorts of observations and data presented here, and such observations are important to the design and success of policies and capacity-building programs for pain and other issues. Medicine, nursing, and healthcare would be improved by broadening the focus of bioethics and clinical ethics from individual patients to the many contextual considerations, interactions, and communities that contribute to each patient's individual identity and well-being, and to each clinician's level of professionalism and empathy.

This article documents the limited availability of hospice, palliation, and pain relief in the Caribbean and provides a foundation for the design of interventions and investigations that will increase the availability of effective pain relief across the Caribbean. Attention to context will contribute to the success of such work.

Notes

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