

## *Healthcare Development Requires Stakeholder Consultation: Palliative Care in the Caribbean*

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Stakeholder consultation is part of the democratic process, embraces respect for persons, and is necessary for upholding the principle of justice. People are more likely to uphold standards they have participated in setting, so stakeholder consultation encourages adherence to societal and institutional standards as these evolve.<sup>1</sup> Stakeholder consultation is also responsive to the call to “resocialize” ethics by contextualizing dilemmas and involving the destitute in choices about their healthcare.<sup>2</sup> In resource-poor settings, such consultation promotes local “ownership” of, and leadership within, development programs, which enhances effectiveness and sustainability. Stakeholder consultation is, therefore, a form of capacity building. To succeed, it must be responsive to regional, national, and individual constraints, including socioeconomic, cultural, and political ones. Several such constraints impact on the demand for, and availability of, palliative healthcare in the Caribbean.

This paper describes attempts to develop palliative care capacity in the Caribbean and illuminates the impact of societal context on stakeholder priorities. It shows the value of consulting and collaborating with local stakeholders when designing development programs. For long-term success, capacity-building efforts must involve consultation with diverse groups within the stakeholder population and facilitate stakeholder participation in designing and implementing development policies and programs.

### **The Caribbean Context**

The paper focuses on the English-speaking Caribbean region, comprising over a dozen independent island nations. Many are economically dependent on tourism. Seven share a common currency. Most are members of the British Commonwealth and have elected, parliamentary governments. The majority of Caribbean citizens and elected officials are people of African heritage who have moved beyond the socioeconomic marginalization affecting African Americans.<sup>3</sup> Hostility against the non-African Caribbean minority exists, but is mitigated in part by the flow of non-African tourists who contribute significantly to local economies.

Caribbean healthcare systems are typically government run, offering free or low-cost services to all. Due to limited resources, it is not unusual for patients

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to wait several hours in a crowded setting to see a doctor. The variety and quality of health services available in the United States and wealthier nations are not routinely available, although most meet World Health Organization (WHO) standards for primary care like childhood immunization. The size and prosperity of each nation impacts the types of medical research it conducts<sup>4</sup> and the standards and types of care it provides.

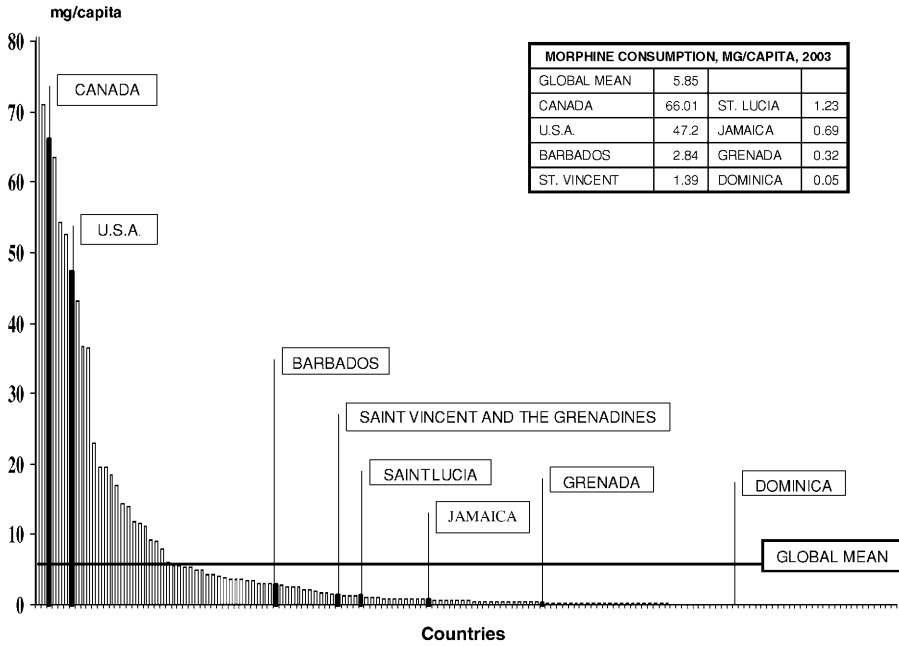
Caribbean nations have similar histories and culture, but the people of each take pride in their cultural differences. English is spoken with different accents and dialects on different islands, and significant socioeconomic, cultural, and geographic differences exist within and between each. Varied levels of poverty persist, but many Caribbean people have homes and lifestyles similar to middle-class Americans. Many use private healthcare at times to deal with acute or chronic illness, pregnancy, or common complaints like backache and indigestion.

When diagnosed with cancer or disease that cannot be managed effectively locally, people with resources travel to North America or Britain for treatment. Others travel to more prosperous Caribbean nations like Barbados, where more services and higher standards of care are available. Those with little money or resources use local services. For terminally ill patients, this sometimes means being sent home with no medical or nursing care, and no social services.<sup>5</sup> Limited provisions for such care sometimes exist, but may not be utilized appropriately by patients or professionals. In addition to using government or private healthcare, people of all incomes use vitamins and/or “complementary” products stocked by pharmacies. Some use “bush medicine” (traditional plants and teas) learned about from family members or friends to treat themselves or supplement conventional care. Pain management and other palliative services are unavailable in most of the public and private sectors. Although the WHO notes that pethidine is eight times less effective than oral morphine and has greater toxicity,<sup>6</sup> pethidine is widely used in the region for acute care.

### *Pain and Its Management*

Globally, opiate importation for medical use is regulated by the International Narcotics Control Board (INCB). Annual importation quotas can be increased, but Caribbean nations have made few requests to do so, and their medical consumption of morphine is below the global mean of 5.85 mg per capita (Figure 1). In 2003, Jamaica consumed 0.7 mg of morphine per capita, compared to 47.2 mg per capita in the United States and 66.0 mg per capita in Canada (another commonwealth nation; Figure 1). Trinidad and Tobago last reported in 1993 (then 0.4 mg per capita), and Antigua and Barbuda last reported in 2002 (less than 0.01 mg per capita). Limited utilization of morphine in the Caribbean reflects demand, but low demand impacts on pain management capacity in public and private settings. Although palliative and hospice care are not widely available, some related services are available in six island nations, including those mentioned above.<sup>7</sup>

A pervasive attitude in the region is that pain is an unavoidable part of life. The pain of childbirth is seen as God’s will and something women must endure. Epidurals are used for cesarian deliveries, but rarely for routine labor. Anecdotally, the standard of care for patients with broken bones or kidney stones does not include aggressive pain relief. Sometimes mild analgesics are



**Figure 1.** Global consumption of morphine in milligrams per capita, 2003. The global mean is calculated by adding the individual milligrams per capita statistics for all countries and then dividing by the number of countries (152). Permission to publish was obtained from the Pain and Policy Studies Group, University of Wisconsin/WHO Collaborating Center, which compiled the data. See [www.medsch.wisc.edu/painpolicy/](http://www.medsch.wisc.edu/painpolicy/). Source: the International Narcotics Control Board; United Nations Demographic Yearbook.

the only treatment given to patients in severe pain. There is a taboo among many doctors and nurses against the medical use of morphine. The few who have seen WHO’s Analgesic Ladder for pain management<sup>8</sup> typically do not follow its recommendations, perhaps because it has received no formal endorsement by national officials. Those who might like to do so may be held back by shortages of opiate medications<sup>9</sup> and unwritten policies guiding their health systems and institutions.

Some nurses reportedly refuse to deliver prescribed morphine to hospitalized patients due to unfounded beliefs about addiction, and lack of sensitization to the need to control pain and overcome the attitude that patients should expect pain until they get well. The resistance of health professionals to treating pain aggressively may involve both cultural mores and personal views. Pain is perceived as unfortunate but unavoidable, morphine is on some level equated with illicit drugs, and many people do not expect or demand pain relief. Moreover, questioning the system or status quo is not always well received and can be demoralizing for those doing so.

There is a pervasive fatalism about suffering and death, which are accepted as inevitable and as God’s will. Regardless of socioeconomic or religious background, a common phrase is “God willing”: for example, “I’ll see you tomorrow, God willing.” The idea that God decides is entrenched in the Caribbean belief system. It impacts peoples’ attitudes about life, politics, and expectations about pain and healthcare. It seems to contribute to reckless be-

havior involving sexual activity and motor vehicles. Pain and suffering are perceived as something willed by God in retribution, for purification, or for an unknown purpose.<sup>10</sup> Most never think to ask for pain relief or improved healthcare. Moreover, limited resources restrict what medications, services, and standards of care are available. Within this context, consequences and accountability are not prominent on health system agendas. A similar fatalism exists in Latin America, where it is attributed to historic, religious, and socioeconomic factors.<sup>11</sup>

### *Practical Limitations*

Health status, systems, and budgets differ between Caribbean nations. Wealthier island nations like Trinidad and Jamaica offer more medical services than smaller ones like St. Vincent and Anguilla. Anguilla, for example, has a population of about 13,000 with a gross domestic product (GDP) of US\$68 million, whereas Jamaica has about 2.6 million people with a GDP of US\$6.6 billion.<sup>12</sup> Smaller nations typically lack technology and infrastructure necessary for intensive care, dialysis, and mammography. Demographics and vital statistics are routinely recorded in small nations, but many do not computerize or analyze the data systematically. Scarcity of trained staff results in poor record keeping and unreliable data, hindering healthcare planning and policy.

The senior national policymaker in healthcare is the Minister of Health, the senior technical adviser is the Chief Medical Officer, and the senior administrator is the Permanent Secretary. These positions are sometimes filled by people outside the health professions, and salaries are lower than in the private sector. Politics contributes to frequent turnover within these positions, and some appointees are frustrated because they lack training in government and health systems. Moreover, the health systems themselves have not changed much in response to evolving needs. Consequently officials have limited ability to function proactively. Informal discussions indicate interest in generating a related training program within regional medical schools.

Burnout is a problem for many Caribbean doctors and nurses due, in part, to working conditions and salaries. Some emigrate to practice in North America or Britain, further reducing local availability of health professionals. On smaller islands, doctors employed full time by their governments may not get vacation time that corresponds with their children's school breaks or other family needs, and some may not get regular vacations at all because no one can cover for them. Those interested in research lack time, energy, and resources with which to engage in studies that pertain even to national statistics or cost effectiveness. Limited resources, inertia, and fatalism within the system hinder innovation and improvement. In this context, what constitutes optimal patient care? What resources, if any, should be diverted from curative to palliative services? Broad stakeholder consultation is a reliable means of finding out.

### **End-of-Life Care in the Caribbean**

After years of living in the Caribbean and hearing disturbing stories about the pain endured by terminally ill friends or family of people I knew, I initiated end-of-life research. Participants were people who had lost and/or been caregiver for a dying loved one within the previous 5 years. Interviews and focus

groups showed that many chose to die at home, but that they received little or no care after leaving hospital.<sup>13</sup> Pain was not effectively managed, sometimes because patients did not take medications as instructed. Although pain was prevalent and distressing, participants were more concerned with financial hardships and the lack of homecare support. Like the deceased, they coped through prayer and emotional support from friends and family.

The study was published<sup>14</sup> in a prestigious Caribbean journal to draw regional attention to the issues. The study itself was a means of stakeholder consultation. Its publication was a means of engaging other stakeholders (health professionals). When presented at a Caribbean medical conference, the audience accepted the data as unsurprising, and acknowledged regional deficits in end-of-life care. These activities generated dialog and probably led some to reassess their own treatment of dying patients. One Minister of Health established a committee to examine feasibility of providing palliative or hospice services, which led to preliminary plans for a small pain clinic.

### Value of Stakeholder Consultation for Palliative Care

Sensitive consultation and analysis proved my expectations wrong: Participants' concerns did not center on pain. Furthermore, consultation elucidated cultural and language-related nuances relevant to data interpretation. Patients who died at home were typically described as "comfortable" because at home, they were cared about, given food they liked, bathed regularly, and in a familiar setting with family and friends. Although comfortable in this sense, further discussion revealed that some were in severe pain. Such nuances of thought and language bear on what sort of health services will be useful and on patient adherence. Thus, systematic consultations add valuable insight, particularly in multicultural settings.

Stakeholder consultation identified Caribbean concerns about the end of life and highlighted health system deficits. To identify what sort of services might be locally effective and sustainable requires further consultation with other stakeholders, including health professionals and officials. Rather than relying on expert opinion about what is needed and how best to provide it, stakeholders must be consulted about *their* priorities and realities. This encourages their commitment to developing and sustaining a suitable response. It reduces misunderstanding and false expectations founded in nuance or preconceived ideas. It elucidates realities that bear on feasibility *before* resources are wasted. Sometimes stakeholders bicker over priorities and control, instead of collaborating toward a goal. Accepting the status quo and being reluctant to accept responsibility increase this problem. Efforts to overcome these, however, can be capacity-building exercises that enhance understanding, cooperation, and commitment to a project.

### Why Consult Stakeholders?

Consulting stakeholders is tedious. There are political channels to work through, and sometimes repercussions. Culture and tradition influence whether people speak openly about certain issues and in what sort of setting people are most willing to speak. It may be difficult to identify who the stakeholders are for a given issue and to determine whether enough groups are represented. There

may not be time or resources with which to consult all relevant groups. Poor or less educated stakeholders may be less articulate and feel intimidated in certain settings. Effective consultation and analysis of responses requires a committed and systematic approach to yield real-life information about what is needed and feasible. This prevents wasting resources.

Externally conceived projects tend to be founded in misinformation and misunderstanding. A new dialysis clinic will be useless if patients cannot use its services and if it lacks equipment, supplies, or trained personnel to maintain its services. The nature of bioethics is to be respectful, beneficent, just, and inclusive. Development of a program based solely on external ideas is none of those things; it imperialistically assumes that someone else knows best. Sensitivity to differences and nuances requires meaningful engagement with stakeholders. This does not constitute relativism. Applying a universal ethical imperative to a concrete situation requires adaptation to context and perspective.<sup>15</sup> Expression and fulfillment of universal values associated with healthcare will vary in different settings.<sup>16</sup> Although several shoes may fit, we tend to buy those we can afford and wear those we find most attractive, comfortable, and appropriate to our activities. Preference and circumstance influence what shoes we wear. Likewise, these influence perceptions, expectations, and how healthcare systems are utilized. Stakeholder consultation illuminates differences beyond our borders, which is crucial to successful development.

Access to healthcare is influenced by complex and overlapping societal factors including justice, education, and access to employment.<sup>17</sup> To be effective, health development programs must adapt to cultural and socioeconomic realities. Debate persists about the standard of healthcare provided to clinical trial participants in less developed nations, and it is increasingly clear that benefits provided ought to vary with local health priorities.<sup>18</sup> To determine what sort of benefits or healthcare will be useful in a given setting and to build capacity to sustain these requires engagement with stakeholders. The variety of around-the-clock care provided by hospice and palliative services in North America is not economically sustainable in most of the Caribbean. Stakeholder consultation clarifies which aspects of such services are most desirable and feasible.

When undertaken systematically, stakeholder consultation is a form of qualitative research that elucidates what participants perceive or want, rather than what someone else believes is needed. Caribbean people may need palliative care, but what aspects of care can work in the context of their national health systems, budgets, and other constraints? Donating money to establish a hospice will not change a health system or the context in which it functions. Moreover, the money may be misused. Collaborating to establish and staff one within the local context takes more effort, but the result is more likely to be sustained and grow. Having a committed local team that owns the effort and outcome may prevent a project from being depleted of resources including the will needed to attain its goals. Capacity-building efforts require collaborative establishment and empowerment of a local team.

Collaborations between local professionals and external experts have improved access to palliative and hospice care. In India, for example, such efforts demonstrated that there was no misuse of opioids when availability was increased for medical use.<sup>19</sup> The WHO and several African governments established teams to identify palliative needs and develop responsive national plans;

they prioritized the greatest needs as pain relief and financial assistance, and the most feasible response as home-based care.<sup>20</sup>

Partnership between international organizations and stakeholders in Mexico, Columbia, and elsewhere has led to revision of national policy and improved availability of opioids for medical use.<sup>21</sup> In Italy, collaborative efforts between doctors, government, and other stakeholders was required to enact policy change and increase medical use of opiates.<sup>22</sup> Obstacles to pain relief in resource-poor nations include restrictive regulatory barriers, misinformation, and exaggerated concerns about the risks of abuse and diversion.<sup>23</sup> Other factors include turnover of government personnel, competition between groups or individuals that interferes with consensus, low priority of pain management in professional education, erroneous beliefs about opioids, and high medication costs.<sup>24</sup> All of these factors impact on Caribbean capacity to provide palliative care.

Incorporating routine provision of palliative measures into a health system takes time and involves diverse stakeholders. In the United States, for example, the Robert Wood Johnson Foundation supports large programs that promote aggressive pain relief (Education for End of Life Care for Physicians and End-of-Life Nursing Education Consortium Training Program), the Joint Commission on Accreditation of Healthcare Organizations requires that hospitals assess pain as a fifth vital sign, and medical school curricula increasingly address geriatrics and end-of-life care. Although these programs improve patient care and set sustainable standards, systematic change is slow, evidenced by the findings that pharmacies in nonwhite communities do not carry adequate stocks of opioids,<sup>25</sup> nearly one in four dying patients have unmanaged pain or dyspnea,<sup>26</sup> and 30% of Americans lose their family savings while caring for a dying family member.<sup>27</sup>

## Conclusions

Guidance, expertise, and funding are needed for health development in resource-poor nations. Stakeholder consultation is an effective means of partnering with governments and other stakeholders and to determine needs and sustainable responses in their unique settings. This view is supported by ongoing Caribbean efforts to improve palliative care through consultation at different levels of seniority among different sectors. The WHO advocates capacity building for palliative care and recognizes that approaches will vary in different settings.<sup>28</sup> In spite of the slow pace at which consultation occurs, it is crucial to sustainable development.

## Notes

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