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**TABLE S1. Overview of the themes and corresponding issues extracted from the reviewed literature in systematic scoping review of palliative and end-of-life care in the English-speaking Caribbean, 2015**

Theme	Description of the situation	Reasons for barriers	Possible ways to reduce barriers
1. Culture and attitudes of health care providers, patients, and those close to them towards terminal illness and death	<ul style="list-style-type: none"> <li>• The region maintains strong religious convictions that influences culture regarding illness. For example, cancer is perceived as God-given punishment in some instances (22, 24).</li> <li>• Pain, incurred from illness, surgery, or childbirth, is perceived as unfortunate unavoidable suffering but part of God’s overall plan (24-26), and many people do not expect or demand pain relief (24).</li> <li>• Historical ties to Europe and geographic proximity to North America have encouraged the adoption of Western norms and values regarding lifestyles and taboos about death. For example, within the family unit, children are separated and protected from visiting dying relatives (21) and indigenous Caribbean medical schools’ curricula put less emphasis on skills, attitudes, and competencies necessary to treat dying patients (21, 32, 33).</li> <li>• A cultural taboo exists among many doctors, nurses, and the public against the medical use of morphine, which is considered an illicit, dangerous, and addictive drug (22, 23, 26, 28). Some hospitalized patients are denied prescribed doses of morphine until obvious signs of distress (23, 25).</li> <li>• Cancer patients underreport pain, believing that complaining distracts</li> </ul>	<ul style="list-style-type: none"> <li>• Poor communication between all parties hinders accurate information sharing regarding illness, death, and dying (22, 34). For example, there is a lack of information on the benefits of screening and early detection of cancer (19). Also, a lack of information fuels the public’s misconceptions about disease processes and pain management (29, 35, 36).</li> <li>• Incorrect information promotes myths, discrimination, and stigmatization on the origins of some cancers, such as cervical cancer, which is the most prevalent type of cancer among Caribbean women (19) and which has a culturally negative association with sexual promiscuity (22).</li> <li>• Misinformation disseminated via the media and social networks reinforces unrealistic beliefs among the public about cardiopulmonary resuscitation (CPR) and the capabilities of modern medical practice in saving lives (34).</li> <li>• Generally, options are either insufficient or lacking for patients and their families to seek and receive accurate and appropriate information about the trajectory of various cancers; medical treatment;</li> </ul>	<ul style="list-style-type: none"> <li>• Government policy, education, and community-based care should be retooled to adequately address the medical, psychosocial, spiritual, and financial needs of cancer patients, families, and caregivers (22), such as with policy that integrates palliative care into public health systems and improves analgesic availability and use (22, 24).</li> <li>• Education campaigns should target health care practitioners and the public. Such efforts should aim at providing the required information necessary for health care practitioners to competently provide palliative and end of life care, and at helping the public to dispel myths and misconceptions about disease processes and available treatment options (22, 24, 32).</li> <li>• Health care practitioners can improve their ability to communicate with patients, families, and caregivers about realistic disease trajectories and viable options (24, 32).</li> <li>• The development of multidisciplinary, community-based palliative care programs comprised of physicians, nurses, social workers, and religious and volunteer communities are also necessary (22,</li> </ul>

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treating physicians from focusing on their illness. Some patients associate the use of opioids (morphine) as a drug of last resort that is prescribed to dying patients, and refuse to use it as prescribed (25).

- In the Caribbean, there is a tradition of home care for the differently abled, mentally ill, the young, and terminally ill elderly (29). It is believed that many terminally ill people choose to die at home (23, 24, 29), which is associated with dignity, comfort, and respect (30, 31).
- Factors influencing futility of care of moribund patients include physician's feelings of guilt, fear of litigation, religious beliefs, and disagreement regarding treatment options (34). Inevitably, the medical profession interprets the death of a patient as a failure (21, 34).
- In Jamaica, members of the public often misunderstand the pathology and treatment of cancer. For example, a cancer diagnosis is frequently regarded as an instant death sentence, and promotes stigma, discrimination, rejection, and abuse by family members and neighbors. Additionally, there is a mutual mistrust between patients and their families and health care practitioners, where the former believe that the latter are not truthful when discussing diagnoses and prognoses of patients' outcomes. The belief is that physicians avoid giving bad news, thinking that their patients will not be able to afford required medical treatments. This mutual mistrust is partly rooted in poor communications among all parties (22).
- The underlying mistrust and perceived feelings of disrespectful attitudes by health care practitioners feed cultural beliefs, leading to resorting to alternative treatment options such as herbal medication and spiritual healers by some (22). Also, traditional medicines are sometimes used in addition to or instead of official medicines (24).
- Faith in God, prayer, and spiritual guidance are critically important cultural support systems for persons at the end of life, particularly when

and psychosocial, financial, and educational support (22, 23).

- An absence of ministry of health policy, and lack of familiarity of existing policy regarding narcotic prescription, impinges on knowledge, attitudes, and practices regarding physicians prescribing opioids for pain (22, 24).

24, 32).

- There is a need for Caribbean guidelines that are specific and sensitive to the different sociocultural and ethnic variations of each country. Such guidelines should be integrated into existing health systems (34).

existing medical options have been exhausted (23, 24, 29).

2. Access to and use of opioids for medical purposes

- The Global Opioid Policy Initiative reported in 2013 that consumption of opioids in most of the Caribbean is variable, with moderate levels of consumption by international standards (1–10 mg morphine equivalents/capita/year) (19).
- The International Narcotics Control Board (INCB) regulates opiate importation for medical use, but Caribbean countries have not requested an importation increase, due to limited use (26). Countries are required to report to the INCB on per capita consumption of opioids, but this information is often incomplete due to the limited resources and infrastructure available to compile and maintain the data, thus hampering the INCB efforts to monitor and encourage use (23).
- Availability, accessibility, and use of opioids for medical reasons are deficient (19, 23, 37) despite the relatively inexpensive cost of oral morphine. Limited hospital stocks of opioids significantly contribute to untreated medical pain (24, 25). In Jamaica, appropriate analgesics are often difficult to access and unaffordable outside hospital settings (29).
- Prescriptions and doses offered to patients in hospital are inadequate to relieve cancer pain (19, 23). Undertreated pain can contribute to poor clinical outcomes, depression, anxiety, difficult doctor-patient relationships, and low public trust in medicine (36).
- A link is suggested between the level of socioeconomic development and opioid use. Lynch et al. (20) recognized that in most regions of the world there is a strong association between development of palliative care and human development as measured by the United Nations Human Development Index (20). This view is supported by other publications (23, 37).
- One of the primary impediments to effective pain relief is the absence of written national policies (23-25, 37). Where policies do exist, their vague interpretation and governance of related laws and regulations contribute to opioid underuse (23).
- Other barriers are of a restrictive regulatory and legal nature (22, 25, 26, 35, 36). Widespread overregulation, along with excessive zeal among drug controllers and policymakers, results in restricted importation of opioids and significantly stunts opioid availability and use within countries (19, 23, 38). Importation restrictions often result in irregular procurement and supply of morphine and other medications (19, 23, 25, 39).
- Existing regulatory systems are burdensome and complex and result in a disincentive for physicians, nurses, and pharmacists to request and administer opioids (25, 37).
- A less visible barrier is the reluctance of pharmaceutical companies and importers to invest in the registration and promotion of products that do not generate significant profits, such as oral immediate-release morphine or oxycodone (19).
- Regulators face the dilemma of providing opioid analgesics for medical use while preventing the abuse of these medications, which are stigmatized as “dangerous drugs” (28, 37).
- The WHO encourages health care professionals to follow its protocol for treating cancer pain (35). The WHO’s guidelines for national narcotics control policies reassure government officials, regulators, and the public at large that the opioid stock is legitimately being used for medical purposes. The guidelines suggest establishing a control system to identify trafficking and diversion of these drugs (40).
- The INCB suggests reforming restrictive government policy that hinders opiate availability (19, 37). Specifically, regulatory authorities can better cooperate and collaborate to increase accessibility of opioids for medical use (26, 37, 38). Medical educators should update their curricula to reflect new clinical and scientific evidence regarding the medical use of opioids to manage pain. Also, health officials and others should conduct periodic education campaigns to update health professionals (including pharmacists) about related developments in evidence-based practice (19, 23, 25).
- Authorities can conduct public education campaigns about pain, palliation, and the effective use of opioids (19, 23, 25, 37).
- Specific examples for increasing medical opioid use include the inclusion and documentation (in medical records) of patient pain assessments as a component part of care for hospitalized patients (19); establishing palliative care services at primary health care facilities with capacity to perform and provide pain assessment, symptom evaluation, and appropriate treatment (38); and designating resources necessary to maintain a sufficient and uninterrupted supply of opioids to meet medical demand (23, 38, 40).

3. Development of services to complement

- The overall state of palliative care practice and development is described in the global categorization of
- A nation’s socioeconomic circumstances can be a major impediment to palliative care
- Uganda is the only developing country categorized by Lynch et al. (20) with advanced integration

palliative care capacity

countries by Lynch et al. (20). Of the six categories, English-speaking Caribbean nations are in groups 1, 2, and 3a. The Group 1 countries (with no known hospice-palliative care activity) are Antigua and Barbuda, Grenada, Saint Kitts and Nevis, and Saint Vincent and the Grenadines. The Group 2 countries (with capacity-building activity) are the Bahamas and Dominica. The Group 3a countries (isolated palliative care provision) are Barbados, Belize, Guyana, Jamaica, Saint Lucia, and Trinidad and Tobago. Belize and Saint Lucia moved from category 2 to 3a between 2006 and 2011 (20).

- A Jamaican study (22) confirms this classification for the country, suggesting that gaps in Government support at regional and national levels are disabling the capacity of health facilities to provide palliative and home care support, leading to long waiting times for services.
- Few countries have palliative care policies (19, 23), and strategies, protocols, and policies addressing needs of persons requiring palliative care are deficient. In addition, appropriate training for health care practitioners is lacking (22).
- Health institutions are unable to digitize and manage medical records (23).
- Working conditions for staff as well as environments to see and treat patients are not ideal for palliative care delivery. For example, there is a lack of private spaces for confidential discussions (22-25).

development (22-26, 35, 36, 39-42). Macpherson et al. (23) suggest that the availability of hospice, palliation, and pain relief in Caribbean middle-income countries is linked to socioeconomic conditions that limit all resources and infrastructure, resulting in substandard health care services compared to those in wealthy nations (23).

- There are numerous other broad obstacles. These include Caribbean health systems maintaining a strong emphasis on curative medicine (21, 25, 29, 36); a shortages of appropriately skilled staff in institutions (23, 24, 41); a lack of incentives to attract and retain skilled staff (23, 24, 41); a lack of training and educational opportunities for staff and health practitioners (22, 23, 26, 35, 36); a lack of policy and palliative care support systems (22, 23, 26, 29, 35, 36, 42); and an absence of an accountability and evaluation system that can hold staff and administrators responsible for their actions or inactions and measure patient outcomes based on treatment (23, 26).

(Group 4). This level of palliative care was achieved by Ugandan stakeholders adopting a public health approach and following the principles outlined in the WHO's 2002 National Cancer Control Guidelines. These include: (i) an assessment of the magnitude of the problem; (ii) setting measurable objectives; (iii) evaluating possible strategies; and (iv) choosing priorities for initial activities (29).

- Additionally, three key measures for facilitating palliative care capacity development are education, increased drug availability, and changes in government policy (29); other publication support this view (24, 39).
- Two examples of developing palliative care services are: (i) government-stakeholder consultations to contextually draw attention to the unique settings and specific needs of each English-speaking Caribbean country (26) and (ii) advocacy for palliative care (43). Another example is utilizing the roles and resources of nongovernmental organizations. For instance, church and community groups can be utilized in combating discrimination, prejudice, and ignorance about cancer as well as providing informal psychosocial and spiritual counselling, bereavement support, and fundraising initiatives to assist households (22).
- Substantial solutions may not require major law changes, to judge from an experience in Jamaica. In that country, recipients of a grant successfully engaged the Ministry of Health in dialogue and lobbied officials there to review the country's pain management policy (39).

4. Unmet palliative care needs

- Outside the hospital setting, there are few if any systems or resources for continued care. For example, there is little or no medical and nursing care or pain relief. And disease registries and palliative care services are incapable of offering patients and their caregivers ongoing emotional, spiritual, financial, and social support, including training

- Cross-cutting and converging issues contribute to unmet needs. This is true for health system limitations (e.g., with resources and infrastructure), as well as for dysfunctional hierarchical relationships among health practitioners. In addition, the lack of appropriate transportation to and

- Programs can be developed and implemented that involve a multidisciplinary team approach that provides symptom management and psychosocial support for patients at home or in institutions (24). Examples likely to be successfully adapted to Caribbean socioeconomic and cultural contexts include

- for informal home care providers (22, 29).
- Inadequate end-of-life care support in the home setting was observed in Grenada, where family members have become indebted due to the high cost of medications, treatment, and the funeral (24).
  - In some countries, the stigma attached to a diagnosis of HIV/AIDS leaves patients socially isolated. A lack of palliative care services (for example, pain and symptom relief, appropriate training of family or other caregivers, food, financial and psychosocial support) further isolates HIV and AIDS patients (29).
  - Persons suffering from sickle cell disease (SCD) are often overlooked when they are in crises, and they have few if any medical or social support services to effectively manage their pain (36).
5. Palliative care research
- Pastrana et al. (27) suggest that health research in the Caribbean has historically been underfunded, has not been prioritized, and is considered a luxury. Other publications acknowledge the lack of health research in the Caribbean (22, 29, 41).
  - With respect to the wider Latin American and Caribbean regions, Pastrana et al. (27) indicate that they lack research agendas and research groups, have limited research cooperation between regional countries, and have limited partnering with researchers in developed countries. Together, these factors result in researchers working in isolation.
- from health facilities complicates accessing medical care for those at home (23).
- Most English-speaking Caribbean nations offer a minimal level of universal health care (36). When there are palliative care services, the public is generally unaware of associated support systems for counseling, financial aid, and home care assistance (24).
  - There is a lack of knowledge and sensitization to the needs of palliative care patients by health care practitioners (26, 37).
- effective pain relief (36) and sensitizing clinicians, administrators, and policymakers to the needed social services that patients and caregivers require (24).
- English-speaking Caribbean government officials, health care practitioners, nongovernmental organizations, and other agents should work together to share expertise, technologies, and best practices, at the local, national, and regional levels, to develop the type of palliative and end-of-life care services that are specific to the needs of each nation (35).
- There are multiple obstacles related to palliative care research. One is that palliative care is not recognized as a discipline, and related research within the health system is not being integrated. Another is that palliative care research lacks national strategies. A third is that the provision of clinical care trumps the development of research capacity. Finally, most research journals are published in developed countries, and their high subscription costs make them prohibitively expensive in many low- and middle-income nations, even when discounts are applied (27).
- Pastrana et al. (27) suggest educating health care professionals through medical curricula and/or continuing education programs as a way to improve the capacity of those who want to do health research within the epidemiological and cultural contexts of their countries and region. Those authors also recommend developing multidisciplinary palliative care research that can stimulate collaboration among Caribbean researchers, and between researchers from developed and low- and middle-income countries, as well as facilitate a transfer of knowledge that can increase representation of Caribbean researchers on established editorial and research review boards.

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**Source:** Prepared by the authors using study data.