PALLIATIVE AND END-OF-LIFE CARE
IN A SMALL ENGLISH-SPEAKING CARIBBEAN COUNTRY: THE CASE OF TRINIDAD AND TOBAGO

A POPULATION - LEVEL STUDY

NICHOLAS JENNINGS

Palliative and End-of-life Care in a small English-speaking Caribbean country, the case of Trinidad and Tobago

A population-level study

Nicholas Jennings

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END-OF-LIFE CARE RESEARCH GROUP
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“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders

TABLE OF CONTENTS

Chapters 2-7 are based on the following publications:

CHAPTER 2

Main Themes, Barriers And Solutions To Palliative And End-Of-Life Care In The English-Speaking Caribbean. A Scoping Review.

Published in: Revista Panamericana de Salud Pública/Pan American Journal of Public Health 2018; 42:e15

CHAPTER 3

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CHAPTER 4

Trends In Place Of Death In A Small Developing Country: A Population-Level Study Using Death Certificate Data

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CHAPTER 5

Developing And Validating A Questionnaire For Mortality Follow-Back Studies On End-Of-Life Care And Decision-Making In Resource-Poor Contexts

Published in: BMC Palliative Care 2020; 19:123

CHAPTER 6

Palliative And End-Of-Life Care In A Small Caribbean Country: A Mortality Follow-Back Study Of Home Deaths

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CHAPTER 7

Medical End-Of-Life Decision-Making In A Small Resource-Poor Caribbean Country: A Mortality Follow-Back Study Of Home Deaths

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INTRODUCTION

1 General Introduction, Research Questions And Outline Of This Dissertation

PALLIATIVE AND END-OF-LIFE CARE IN A SMALL ENGLISH-SPEAKING CARIBBEAN COUNTRY: THE CASE OF TRINIDAD AND TOBAGO

1.1 INTRODUCTION

The International Association for Hospice and Palliative Care defines palliative care as; "the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers"(1). Worldwide, the need for palliative care is great and is increasing due to the burden of ageing of the world's population and increasing incidence of chronic and degenerative medical conditions (2).

In high income developed countries substantial progress has been made in the development of palliative and end-of-life care. Supported by robust population level research considerable investment has been made to ensure quality end of life outcomes (3). Research on the social and clinical circumstances of dying, for example, has brought to the fore important topics such as: access to palliative care, choice in the place of care and death – private homes, care homes or hospices – (4-14) or the development of appropriate laws and policies that address ethical issues such as withholding or withdrawing care and even medical aid in dying (15-20). Furthermore, palliative care is considered best practice in alleviating the relief of suffering at the end of life and is an important indicator of quality care when it is implemented early in the trajectory of a life limiting condition (21).

Although the historic drive to develop palliative care emerged from caring for patients with cancer, patients with other conditions and chronic diseases associated with serious health-related suffering (SHS) like cardiovascular and respiratory diseases, endocrine conditions like diabetes mellitus and infectious illnesses like acquired immune deficiency syndrome (AIDS) or the recent emergence of Coronavirus disease 2019 (COVID-19) can receive palliative care and benefit from a reduction of symptom burden and improved quality of life (22,23). However, outside of Western Europe, the United Kingdom, North America and Australia, the majority of people needing but not receiving effective palliative care or even access to care live in developing and resource-poor regions or countries (24). *Resource-poor relates to the limited capability to provide care for life-threatening illness due to a lack of necessary human and material resources and consequent services, inadequate education and training for health care providers, and a lack of governmental policies to support the provision of palliative care* (25,26).

Only about 14% of people worldwide who need palliative care currently receive it (27). For children, 98% of those needing palliative care live in low- and middle-income countries with Africa contributing approximately half of this need. A 2019 World Health Organisation (WHO) survey on non-communicable diseases conducted in 194 Member States found that palliative care funding was available in 68% of countries and only 40% of them reported that the services reached at least half of patients in need (28). The WHO has acknowledged the existence of a palliative care needs gap in low- and middle-income countries (24), as many have yet to consider palliative care as a public health problem and include it in their health agenda and existing health care services.

In resource-poor settings, for example, a major public health challenge is to ensure that minimum standards are available to offer pain relief or other symptom control, psychosocial, emotional and spiritual support. In countries with a poor health infrastructure but a tradition of strong family support, home-based access to care can be a way of achieving quality care and coverage. Understandably, resources available to allocate to palliative care in low- and middle-income countries vary and important traditions and cultural sensitivities towards health, terminal illness, dying and death must be considered when a palliative care programme is implemented (29).

In a majority of low-resourced and developing countries, complex factors including the lack of a research culture and infrastructure and lack of incentives for research activities has relegated health research as a luxury, which is often funded by external sources (30,31). A major obstacle and continuing challenge to the further development of palliative care in developing countries is a lack of information surrounding the circumstances of dying from chronic and degenerative medical conditions, which limits in-depth exploration of how such countries are providing care. Consequently, dying from a terminal illness and the related experiences encountered at the end of life by patients, their family and caregivers in these countries are largely unexplored through systematic research (32,33).

1.2 THE ENGLISH-SPEAKING CARIBBEAN

English-speaking Caribbean nations are twelve territories with comparable colonial experiences (former British) where English is the official language, they include: Antigua and Barbuda, The Bahamas, Belize, Barbados, Dominica, Grenada, Guyana, Jamaica, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines and Trinidad and Tobago, Figure 1.

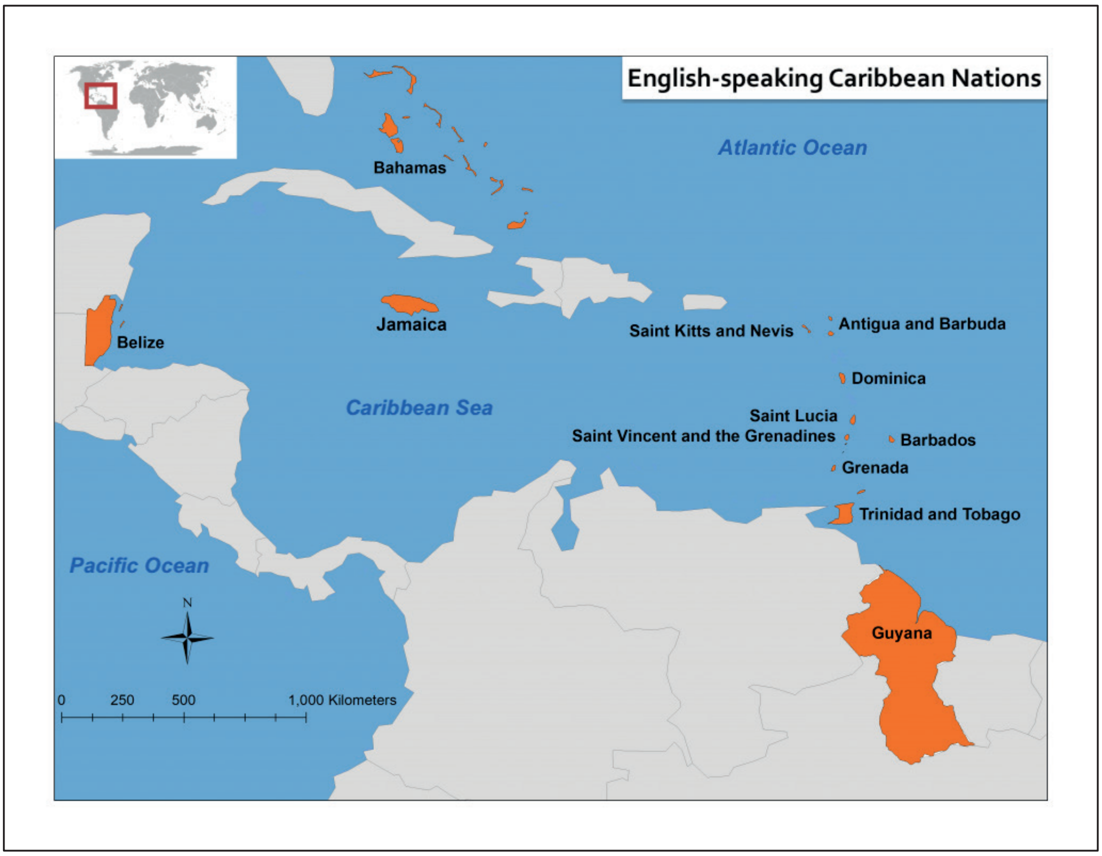


Figure. 1. Map of English-speaking Caribbean nations. Source: Caribbean Cooperative MRV HUB (34). Adapted by the author.

These nations are connected culturally and socially, share similar political and educational structures and socioeconomic links (35) such as the Caribbean Community and Common Market (36), and are classified by the World Bank as upper-middle to high income developing countries (37). Mostly Island nations, they are members of the United Nations Conference of

Small Island Developing States (SIDS) that are a group of developing countries susceptible to vulnerabilities, for example: their geographic position can be remote with limited access by international travel connections and exposure to natural hazards like hurricanes; small populations dependent on a narrow range of exports, limited access to affordable international finance that can restrict economic activity, and they are extremely vulnerable to exogenous shock (38).

The World Bank's classification of these countries as upper-middle to high income is primarily based on the calculation of 'gross domestic product (GDP)', an indicator of well-being and development that is exclusively based on material wealth and used to classify a society's standard of living and to compare wealth among countries (39). However, GDP per capita may not be the best index to measure standard of living within a country as economic inequalities (poor-rich divide) are not represented nor are non-material societal values like leisure, environmental quality or levels of health and education (40).

Table 1., offers a level of descriptive detail and comparison of information on; financial health systems characteristics (41-43), total population (44), life expectancy (41), and land area by country (45). Gross Domestic Product per capita (PPP based) is GDP converted to international dollars using PPP rates divided by the total population. Therefore, an international dollar has the same purchasing power over GDP as a United States dollar (USD) has in the United States (42). Out-of-pocket payments are expenditures borne directly by the patient. A high level of out-of-pocket expenditures is an indication of weaker health systems and lower levels of health services coverage (43). Information presented in the table vary from country to country, for example, GDP per capita ranges from $36,297 (USD) in the Bahamas to $7,109 (USD) in Belize and health spending per capita and percent of our-of-pocket expenditure ranges from $2,206 (USD) and 40% in Trinidad and Tobago to $532 (USD) and 17 % in Jamaica.

Latin American nations (including Cuba and the Dominican Republic) average health spending per capita was $1,100 (USD), which was more than the average health spending for the English-speaking Caribbean $975 (USD). However, the percent of out-of-pocket expenditure was less for Latin American nations 30%, compared to the English-speaking Caribbean 36% (43). This is perhaps an indication that value for money in health care is not optimal and efficiency of national health expenditure (public and private) in English-speaking Caribbean nations is lacking.

Table 1. Dashboard on country data.

Country	*Total expenditure on health as % of GDP (2014)	†GDP USD PPP per capita (2017)	‡Health spending USD PPP per capita (2017)	‡Out-of-pocket expenditure on health (%) (2017)	§Total population (2017)	*Life expectancy at birth (2019) M / F	¶Land area (sq. km)
Antigua & Barbuda	5.54	19,840	1,071	35	95,430	74 / 77	440
Bahamas	7.74	36,297	1,746	31	381,760	69 / 76	10,010
Barbados	7.47	15,789	1,317	46	286,230	74 / 77	430
Belize	5.79	7,109	473	24	375,770	71 / 77	22,810
Dominica	5.49	11,304	636	31	71,460	NA	750
Grenada	6.1	16,217	714	52	110,870	70 / 75	340
Guyana	5.25	12,005	385	32	775,220	62 / 69	196,850
Jamaica	5.36	9,598	532	17	2,920,850	74 / 77	10,830
Saint Kitts &Nevis	5.08	25,360	1,442	48	52,040	NA	260
Saint Lucia	6.72	14,946	661	45	180,960	71 / 77	610
Saint Vincent & the Grenadines	8.63	12,245	522	31	109,830	71 / 75	390
Trinidad & Tobago	5.93	26,448	2,206	40	1,384,070	72 / 79	5,130

Abbreviations: GDP – Gross Domestic Product; USD – United States Dollar; PPP - Purchasing Power Parity; M – Male; F – Female; NA – Not Available

Table prepared with data from sources listed below:
***World Health Organisation (41)**
†Source: The World Bank (42)
‡Source: OECD (43)
§Source: The World Bank, populations (44)
¶Source: The World Bank, land area (45)

English-speaking Caribbean countries have similar health structures based on a model that consists of a centralized ministry of health and peripheral health facilities. Health services delivery is through a mixture of public and private providers where government health services are mainly free at the point of delivery (46). Since 2013, the Caribbean Public Health Agency (CARPHA) is the single common regional public health authority (47), and a Caribbean palliative care association was formed in 2019 (48).

The Caribbean, including English-speaking nations, has a long migratory history. Mexican emigration, mainly to the United States of America, receives much attention in Latin America and the Caribbean. It was estimated in 2017 that 10% of that population lived abroad but estimates for the Caribbean population living abroad reaches 22% (49). For example, 2013 data suggests that most migrants were from Guyana and Saint Vincent and the Grenadines with an emigrant population of 58.2% and 55.5%, respectively, compared to the size of the population living at home. The largest number of immigrants from the English-speaking Caribbean living in the United States are from Jamaica, Guyana, and Trinidad and Tobago (50). Possibly a consequence of decolonialisation, Caribbean migrants have been leaving their home countries – mainly immigrating to North America and the United Kingdom – motivated by pursuing higher education or prospects of economic stability in the form of employment or better paying employment with better working conditions, but also in search of better and more secure environments with political and social (e.g., less violent crime) stability and a relatively higher standard of living.

What might be considered a benefit of migration is the remittances sent by migrants to their families in home countries. Remittances assist in providing financial resources for trade and investment that helps boost the home country's growth (49). However, an implication of emigration is the 'brain drain' caused, as migrants are often young and educated, many of whom are health workers, especially nurses followed by physicians (50), as well as engineers and other skilled professionals (49). A 2017 Pan American Health Organization survey of health professionals in English-speaking Caribbean nations and territories indicated that about 60% of health professionals including, physicians, nurses, leadership and administration personnel and other allied health professionals would migrate if given the opportunity in the future (51). This departure reduces the skilled labour force and weakens economic and social growth of the home country (50), but also can negatively affect efforts to improve health care in home countries like the attainment of universal access to health and universal health coverage (51).

1.3 SOCIODEMOGRAPHIC CHANGES

Important epidemiologic and social developments have brought about changes to the population of the Caribbean. Improvements in medical technologies and treatments, and advancements in public health and access to health care have resulted in an increased life expectancy (52).

In Latin America and the Caribbean life expectancy is projected to increase to 80.7 years for women and 74.9 years for men between 2025 and 2030 (53). In 2017, 13% of the population were aged 60 years and older (54), and by 2030 this demographic is expected to account for more than 17% of the total population in this region (55). It is anticipated that the aging population trend will be associated with a decrease in fertility, which can lead to drastic changes in the aging index (i.e., the ratio of older people to people under the age of 15), which could reach 142 older persons for every 100 children by 2040 (54). The leading causes of death have also shifted from communicable diseases, for example, malaria and tuberculosis to non-communicable diseases (NCDs) like cardiovascular diseases and malignancies. The reality is that non-communicable diseases are now the leading cause of premature deaths, representing nearly 50% of all deaths of persons under 70 years of age (56), however, of the Americas the Caribbean region is the most worst affected by non-communicable diseases (56,57).

These developments increase the possibility that a growing number of persons will suffer and eventually die from chronic conditions, deaths likely preceded by prolonged periods of illness requiring and would greatly benefit by palliative care. About 40 million people globally needed palliative care in 2020, 78% of whom live in developing countries. This global need is expected to continue growing driven by the rising burden of ageing populations, and non-communicable diseases, particularly when cure is no longer possible (58). However, a number of broad and significant barriers restrict access to palliative care including: the lack of national health policies and systems that include palliative care as a health priority, the absence of awareness of palliative care among health professionals and limited training of physicians in palliative medicine (58-60); overly restrictive regulations of opioid pain management (opioid analgesics are essential for treating serious health-related suffering associated with many advanced progressive conditions including those of non-communicable diseases); opiophobia or the fear, prejudice and misinformation about the appropriate use of opioids for medical use; and the curative focus in medicine on extending life while caregiving and quality of life near death is neglected (61-65).

1.4 PALLIATIVE CARE AND PAIN RELIEF

A 2017 global comparison of countries compared palliative care provision with the relationships of the World Bank Income Level (WBIL), Human Development Index (HDI), and Universal Health Coverage (UHC). Countries that were ranked high on these indices also had higher levels of palliative care development. The highest level of palliative care development and provision (category 4b: Palliative care at advanced stage of integration) was available for only 14% of the World population concentrated mainly in European countries. With the exception of Barbados (4b), English-speaking Caribbean countries were in categories 1 – no known palliative care activity, to 3b – generalized palliative care provision, which still lacked a national initiative (66). It appears that little attention is given to palliative and end-of-life care in many of these countries, as palliative care is absent from health agendas (27). Common barriers such as culture and attitudes of health care providers, patients and their families towards terminal illness and death, and the lack of empirical information on the provision of and access to palliative care have slowed its development (67). Furthermore, the lack of original research on palliative and end-of-life care issues on populations living in the Caribbean makes it difficult to understand the complexity of issues, furthermore, regional health research including that for palliative care has historically been underfunded (26,30,31,33,59,60,67,68).

Core components of universal health coverage are palliative care and pain relief, which are considered to be key elements of quality health care, but the need for palliative care and pain relief has been largely ignored (69). Of the 56·2 million deaths recorded worldwide in 2015, 45% experienced serious health-related suffering and possibly died with undertreated pain, 80% of those were from developing regions where palliative care and pain relief is scarce or non-existent (61). Less than 15% of the world's population lives in a high-income country, but they consume more than 90% of opioid analgesics (70). For example, the annual distribution of morphine is more than 68,000 mg per patient in need of palliative care in Canada and 55,000 mg per patient in the United States of America but only 5 mg per patient in need of palliative care in Haiti (62).

Indeed, in many developing countries and resource-poor regions of the world, access to medical opioid analgesics is either lacking or absent (71). As was reported to the International Narcotics Control Board (INCB), although the overall trend in the Caribbean indicates an increased use of opioids for medical purposes from 2001-03 to 2011-13, there were considerable variations among countries and consumption remained below an adequate level (72), Table 2. The defined daily doses for statistical purposes (S-DDD) is a technical unit of measurement and not a recommended prescription dose. This in recognition that no internationally agreed standard exists for opioid medicines and therefore provides a rough measure to rank opioid use of countries. Levels of use, expressed in S-DDD per million inhabitants per day, are calculated with the following formula: annual use divided by 365 days, divided by the population in millions of the country or territory during the year, divided by the defined daily dose. The defined daily dose (DDD) is the assumed average maintenance dose per day for a drug used for its main indication in adults (73).

Table 2. Mean per-annum S-DDD and DDD use at the country level in the years 2001–03 and 2011–13, ordered by 2011–13 S-DDD use, and absolute changes in use.

Country	S-DDD use per million people per day			DDD use in total (per annum)		
	2001–03	2011–13	Absolute change	2001–03	2011–13	Absolute change
Antigua & Barbuda	96	0	-96	2316	0	-2316
Bahamas	293	425	132	32077	51069	18992
Barbados	438	409	-29	42648	40864	-1784
Belize	0	73	73	0	8325	8325
Dominica	74	76	2	1951	2083	132
Grenada	72	53	-19	2530	1935	-595
Guyana	27	123	96	8024	33808	25784
Jamaica	58	133	75	54711	132751	78040
Saint Kitts & Nevis	85	0	-85	1204	0	-1204
Saint Lucia	131	0	-131	7167	0	-7167
Saint Vincent & the Grenadines	84	254	170	3442	9914	6472
Trinidad & Tobago	0	199	199	0	95487	95487

Abbreviations: S-DDD=defined daily doses for statistical purposes; DDD=defined daily dose
Table prepared with data from a LANCET publication (74).

English-speaking Caribbean countries have similar cultural and colonial histories, they co-operate economically within a common market, share and utilise health information and resources through a common public health agency, and have similar political and educational structures. Indigenous Caribbean studies concluded that the need for palliative care services is driven by demand from an aging population and increasing morbidity from chronic diseases, cancer and HIV/AIDS as well as the need for health care policy, training of staff, education, and access to effective analgesia (67,75-79). These are commonalities that could allow for some generalisation that the case of one Caribbean country (Trinidad and Tobago) – i.e., investigation of the circumstances of dying from illnesses indicative of a palliative care need – may be applicable in other Caribbean countries.

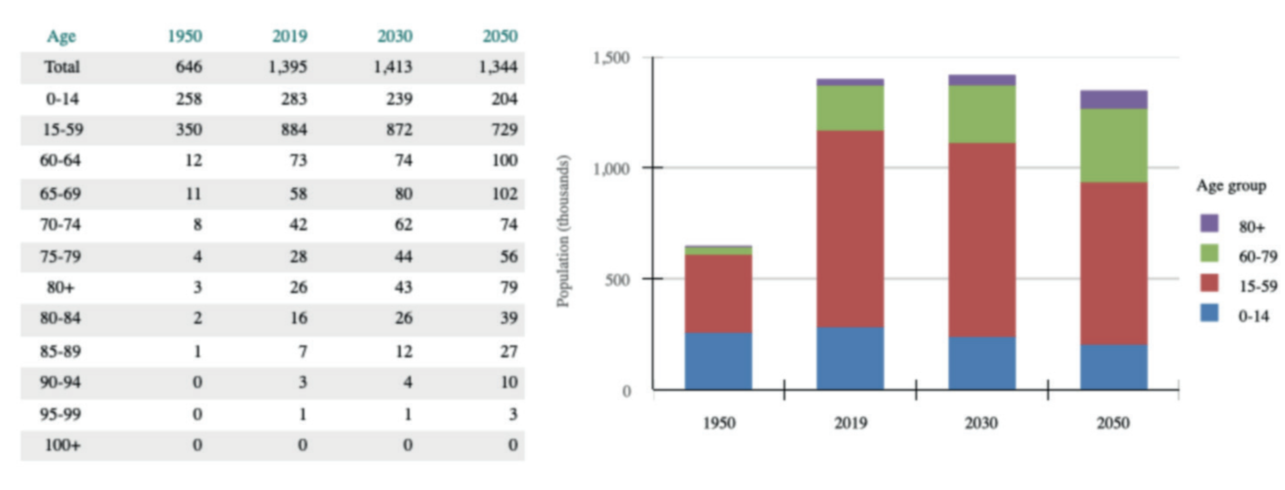
1.5 TRINIDAD AND TOBAGO

Similar to most other English-speaking Caribbean countries Trinidad and Tobago (T&T) has a bipartite health care system. Public services are provided free of charge at the point of contact including free prescription drugs and other pharmaceuticals, but private health care services are paid either out of pocket by patients or to varying degrees by their private health insurance. The Ministry of Health is the national monitoring and regulatory body for organisations and institutions that produce health goods and services. The provision of health care is decentralised into five Regional Health Authorities (RHAs): Eastern, North Central, North West, South West, and Tobago, which are autonomous bodies that own and operate health facilities in their respective regions (80).

In 2019 the population was estimated at 1.4 million of which 18.2% was 60 years and older, by 2030 the population is anticipated to increase slightly to 1.41 million and then decrease to 1.34 million by 2050. However, persons 60 years and older are anticipated to steadily increase to 24.5% by 2030 and 36.5% by 2050 (81), Figure 2.

Of Caribbean countries T&T has one of the highest rates for morbidity and mortality from non-communicable or chronic diseases, which were estimated to have accounted for 81% of all deaths in 2016. Cardiovascular diseases 33%, cancers 15%, diabetes mellitus 15% and chronic respiratory diseases 3% were among the main causes of death (82), all medical conditions indicative of palliative care needs (83).

Figure 2. T&T population spread from 1950 predicted to 2050 categorised by age



Age	1950	2019	2030	2050
Total	646	1,395	1,413	1,344
0-14	258	283	239	204
15-59	350	884	872	729
60-64	12	73	74	100
65-69	11	58	80	102
70-74	8	42	62	74
75-79	4	28	44	56
80+	3	26	43	79
80-84	2	16	26	39
85-89	1	7	12	27
90-94	0	3	4	10
95-99	0	1	1	3
100+	0	0	0	0

Source: United Nations Department of Economic and Social Affairs, Population Division. Profiles of Ageing 2019 (81).

Palliative care in T&T was reported as ‘Isolated Palliative Care Provision’ where there is an absence of a national commitment to palliative care practice, and existing services are limited and lacking in governmental, social and financial support, for example, unreliable availability of morphine at the nation’s health institutions and a small number of hospice and palliative care services in relation to population size; included in this category was Jamaica (66). Available service provision includes: in Trinidad there is a nurse led home-based oncology/palliative care service in the eastern (RHA), a government operated palliative care unit (comprised of a 12-bed out-patient service and hospital consult) in the north-central (RHA), two 12-bed non-governmental hospices in the north-west (RHA), and in the Tobago (RHA) a nurse-led home-based palliative care service. However, a hospital-based outpatient palliative care clinic in the Trinidad south-west (RHA) was suspended in 2019 citing lack of human resource. Efforts to revive it in 2020 were abandoned due to shifting priorities of the Regional Health Authority relating to the emergence of the Coronavirus disease 2019 (COVID-19) (84). A national palliative care association began operating in 2011.

In addition to the lack of clinical infrastructure, there is also a lack of general research infrastructure to support innovation and policy in this domain. Numerous obstacles and challenges of doing research in developing countries exists, and a common theme of ‘*a lack of information and lack of original studies*’ on, for example, palliative care in the Caribbean persists (26,59,60,67,68). Because there is a lack of data from any Caribbean country through large-scale robust studies conducted to confirm the circumstances of dying and the provision of palliative care, I undertook this research project as I wanted to better understand and offer more insight in the field but importantly to generate data, knowledge and evidence, around palliative and end-of-life care from a Caribbean context. As a resident and national of T&T, I present the case of this small low-resourced high-income developing country as an example that robust public health research can be done in such a context. Perhaps the methodology used and findings from this thesis can offer fertile ground to conduct further detailed research in T&T, or other similar Caribbean or developing country or resource-poor regions concerning how palliative and end-of-life care is being provided and what value such research may have for policy and health care.

Due to a lack of networks and support for health researchers in T&T, my affiliation with the End-of-Life Care Research Group at Vrije Universiteit Brussel, Belgium and St. George's University school of medicine in Grenada (my graduate alumnus) were strategic and practical, as these institutions provided the necessary technical expertise and guidance to do these types of studies, which are the first of their kind in Trinidad and Tobago.

1.6 STUDY OBJECTIVES AND RESEARCH QUESTIONS

The main objectives of this dissertation are to describe the circumstances under which persons die and to describe the medical care and treatment a person received prior to their death in Trinidad and Tobago.

The following are the main aims and research questions that guide this dissertation:

I. The first aim is to identify and comprehensively review the knowledge and knowledge gaps documented in the literature on palliative and end-of-life care in the English-speaking Caribbean region. The following research questions will be answered:

1. What are the common themes documented in the literature on palliative and end-of-life care in the English-speaking Caribbean? What are the barriers and suggested im-

provement strategies to further develop palliative care in English-speaking Caribbean nations?

II. To compensate for the lack of research data, the second aim is to explore and use available routinely collected population-level administrative data on dying in Trinidad and Tobago. The following research questions will be answered:

1. Where do people die in Trinidad and Tobago? What are the social circumstances and characteristics associated with their place of death?
2. What is the trend in the place of death, and what are the implications for end-of-life care and policy practice related to trends?

III. The third aim is to generate reliable and representative data and insight regarding end-of-life care and medical end-of-life decisions of non-sudden deaths in Trinidad and Tobago, and identify and describe important differences in end-of-life care and decision making between sociodemographic and clinical groups. The following research questions will be answered:

1. Is it feasible to conduct a representative national survey by adapting a questionnaire on palliative and end-of-life care to the socio-legal context of Trinidad and Tobago?
2. What are the characteristics of palliative and end-of-life care and treatment and medical decision making at the end of life in Trinidad and Tobago?
3. What are the characteristics of caregivers providing palliative and end-of-life care for persons dying at home in Trinidad and Tobago?
4. What is the sociodemographic and clinical profile of patients who receive palliative and end-of-life care at home in Trinidad and Tobago? What are the characteristics and incidence of different types of medical end-of-life decisions made at the end of life for persons dying at home?
5. Is there a difference in medical end of life decision-making in Trinidad and Tobago depending on the physicians’ formal palliative care training?

1.7 METHODS

1. SCOPING LITERATURE REVIEW (RESEARCH AIM I.1)

A systematic scoping review was done because we wanted to broadly explore the subject of palliative and end-of-life care in English-speaking Caribbean nations. The small volume and limited number of documented studies necessitated including a wide range of peer-reviewed and grey literature to provide greater conceptual clarity about the specific topic. This method is considered appropriate to gain information on a broad topic and rapidly map key concepts as well as the main sources and types of evidence available. Methodological details can be found in Chapter 2.

2. POPULATION-LEVEL ANALYSIS OF ROUTINELY COLLECTED ADMINISTRATIVE AND SUPPLEMENTARY HEALTH DATA (RESEARCH AIMS II.1-2)

We conducted population-level analyses of routinely collected death certificate and supplementary health data. In Trinidad and Tobago physicians are obliged to complete the medical certificate of cause of death, which are classified using the International Statistical Classification of Diseases version 10 (ICD-10) codes. Medical death certificates also contain sociodemographic information of the decedent. The national death registry the Central Statical Office (CSO) collects and processes public administrative data including mortality data into a national database. Data were deidentified so ethics approval was not necessary as per national regulations. We negotiated access to the data from the CSO and two studies were done using datasets. The unit of analysis was the recorded death of residents and visitors 18 years and older, in Trinidad and Tobago for the study period. We retained categories for place of death as they appeared on medical death certificates: private home, government hospital, nursing home or non-government hospital and other (e.g., public places, workplaces, roads and private geriatric homes).

I. ***PLACE OF DEATH IN 2010.*** At the time the study was done, 2017, the most recent available year of completed mortality data was 2010 (N=10,221). The CSO also provided supplementary census data (community classification of urbanisation), and data on percent of the population living in an urban setting in 2010. The Ministry of

Health provided health resource data, i.e., the number of government hospital beds (n=2009) and the proportion of beds per Regional Health Authority (RHA): North-West, North-Central, South-West, Eastern and Tobago. Age, gender and main underlying cause of death were extracted from the records including race/ethnicity, following the CSO's usage of terms for race/ethnicity, i.e., (East Indian, black, mixed, white and Chinese) for our analysis.

II. ***PLACE OF DEATH TREND ANALYSIS 1999 – 2010***. The study was done in 2018 and due to coding delays, fully completed and reliable datasets were only available for the years 1999 through 2010. Demographic characteristics of decedents (N=118,703), including the year, age, gender and main underlying cause of death, were extracted from the records. A subcategory of persons who died from some of the most common chronic life-limiting conditions that are indicative of a palliative care need was considered. These included the following diseases and their corresponding ICD10 coding: cardiovascular disease (I00–I52, I70–I99), malignancies (C00–C97), respiratory disease (J00–J99), diseases of the nervous system (G00–G99), cerebrovascular disease (I60–I69) and diabetes mellitus (E08–E13). All remaining causes were grouped into the category other.

3. POPULATION-BASED MORTALITY FOLLOW-BACK STUDY BASED ON DEATH CERTIFICATES (RESEARCH AIMS III.1-5)

In 2018 a population-level mortality follow-back study based on a representative sample of death certificates of home deaths was done. The sampling framework was obtained from death certificates that were sampled at the CSO. A mortality follow-back approach was used as it is an efficient means to collect robust population-based information on the last days or months of life. Ethics approval for this study was granted by the Ministry of Health of Trinidad and Tobago (no file number available: The Ministry does not catalogue approvals issued for research). The Trinidad and Tobago Medical Association was an invaluable and neutral consultant and partner in the planning and conduct of this study. One of our aims is to generate reliable and representative data, and to achieve this we developed and validated a survey instrument that was used to gather information from general practitioners on the care and treatment of their patients prior to death. Three reports were written to this effect. This section briefly introduces the research methods used to develop the questionnaire that was used in the mortality-follow back study followed by the two studies. Full details of the Questionnaire development study are explained in Chapter 5, and mailing procedure for the survey in Chapters 6 and 7.

I. ***QUESTIONNAIRE DEVELOPMENT***. A questionnaire was developed and cognitively tested to collect population-based information in a standardised manner on the medical characteristics of palliative and end-of-life care, (i.e., care provided in the last 30-days before death), and the circumstances of dying. Modelled on a questionnaire originally developed in the Netherlands in 1990, which was successively used in slightly adapted versions in other countries between 1997 and 2016, our questionnaire was adapted by cognitive testing and face validation to ascertain it was suitable and relevant to the context of Trinidad and Tobago. Face-to-face interviews were done in two phases from November 2017 to March 2018. Purposive sampling was used as we deliberately sought participants who were logically assumed to represent the population of physicians with knowledge and experience with end-of-life care. Eighteen different physicians were interviewed.

II. The questionnaire used in the mortality follow-back study yielded two reports, one focused on ***PALLIATIVE AND END-OF-LIFE CARE*** and the other on ***MEDICAL END-OF-LIFE DECISIONS.*** A random sample of Trinidad and Tobago residents aged 18 years or older, who died at a private home between March 1 and August 31, 2018, was drawn from the death certificates at the CSO; the sampling fraction was 1 in 2. The general practitioner certifying each death in the sample was invited by postal mail to complete a questionnaire about the end-of-life care in the specific case. A four-page questionnaire was mailed to the certifying physicians of all sampled deaths. In total 752 deaths were sampled. The neutral third party, the Trinidad and Tobago Medical Association, was involved in the mailing procedure as an intermediary between responding general practitioners, researchers, and the CSO to maintain general practitioner anonymity and guarantee that completed questionnaires could never be linked to a particular patient or physician. Only deidentified patient sociodemographic information was linked to the corresponding completed questionnaires. This procedure included the use of a randomly assigned unique number that was affixed to each mailed questionnaire. As completed questionnaires were received by the third party, a new unique number was affixed and the initial one removed along with any identifiers.

1.8 OUTLINE OF DISSERTATION

This doctoral dissertation is divided into three parts and contains eight chapters. Following this introduction chapter, chapters 2-7 are based on articles which have been published, accepted, or submitted for publication in peer-reviewed journals, and the final part is the general discussion. All these chapters can also be read independently. The three main aims of this dissertation are addressed in separate parts. Each part consists of one or more chapters that answer the specific underlying objectives and research questions.

GENERAL INTRODUCTION describes the rationale for this dissertation as well as the aims, objectives research questions and methodology.

PART I offers a detailed presentation and discussion on the literature review of palliative and end-of-life care in the English-speaking Caribbean nations, and addresses the first aim of identifying knowledge and knowledge gaps in the literature, **(CHAPTER 2).** This part also serves as background information for the questionnaire development discussed in ***Chapter 5***.

PART II addresses the lack of research with existing data, by using available administrative and routinely collected data to do population-level studies in resource-poor contexts. We explore and investigate the place of death using medical death certificates **(CHAPTER 3)** and discuss the implications for the availability of palliative care in relation to an exploration of changes in the place of death over time **(CHAPTER 4)**.

PART III addresses issues on generating new data and investigating the circumstances of end-of-life care and dying from serious illnesses in Trinidad and Tobago using a mortality follow-back study. **(CHAPTER 5)** describes in detail the process used to develop and validate a questionnaire for use in a post-mail survey, and the implications this may have for other Caribbean or developing countries. In **(CHAPTER 6)** we describe the multistage mailing procedure used for the mortality follow-back survey and describe the palliative and end-of-life care persons received prior to their deaths at home. General practitioners formal palliative care education in relation to their medical end-of-life decision-making is examined in **(CHAPTER 7)**.

The final chapter of the dissertation, includes the main findings of the study, a reflection on its strengths, limitations and a thorough discussion of lessons learnt. First, I touch on the challenges and opportunities of doing research in a small resource-poor country. Second, I discuss the findings in this context in relation to the challenges of providing palliative and end-of-life care to those that need it. Lastly, I formulate the implications of my research for education, practice, and policy.

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PART I IDENTIFYING KNOWLEDGE AND KNOWLEDGE GAPS IN THE LITERATURE

2 Main Themes, Barriers And Solutions To Palliative And End-Of-Life Care In The English-Speaking Caribbean. A Scoping Review

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ABSTRACT

Objectives. To identify common themes documented in the literature on palliative and end-of-life care in English-speaking Caribbean small island developing states (SIDS), and to describe barriers, improvement strategies, and suggested ways forward.

Methods. In 2015, we conducted a systematic scoping review of relevant literature identified through the MEDLINE and Web of Science databases. We and supplemented that with searches of other electronic and hard-copy sources to map key concepts and summarize themes.

Results. Primary data and other literature from and about English-speaking Caribbean nations are relatively scarce. The available literature offers an overview of the existing situation in the region and explores why palliative and end-of-life care is limited there. The review identifies barriers in five main areas recurring across this literature: i) culture and attitudes of health care providers, patients, and those close to them towards terminal illness and death; ii) opioid availability and use; iii) limited development of palliative care services; iv) unmet palliative care needs; and v) limited research on palliative or end-of-life care.

Conclusions. Our analysis helps to document the need for palliative and end-of-life care in Caribbean SIDS and highlights suggestions for moving forward with related practice, policy, and research.

BACKGROUND

World Health Organization (WHO) data suggest that annually 20 million people worldwide, of whom 69% are adults over the age of 60, require and benefit from palliative care (1), which is defined as an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness (2). The Pan American Health Organization (PAHO) predicts that by 2020 there will be 100 million people over the age of 60 in Latin America and the Caribbean (3), a growing number of whom will die from chronic and life-threatening conditions associated with prolonged periods of illness (4).

In the English-speaking Caribbean, little attention is given to palliative and end-of-life care. Further, despite an aging population likely to require palliative care, many of these countries do not consider palliative care a public health need, nor is it integrated into their health systems (5). Although WHO recognizes the delivery of palliative care as a major public health challenge in these countries (6), there is little empirical information on the provision of and access to palliative care (7, 8).

A recent article by Maharaj and Harding (8) that focused on palliative care, needs, models, and interventions of care in the Caribbean contributed significantly to understanding the nature of palliative care in the region. Their review highlighted the need for palliative care services, which are driven by demand from an aging population and increasing morbidity from cancer and HIV/AIDS; for health care policy, staff training, and education; and for access to analgesia. However, the study included only peer-reviewed papers.

Given the scarcity of information on palliative and end-of-life care in the Caribbean, a broader exercise, such as a systematic scoping review, could map a wide range of literature, envisage gaps and innovative approaches, and provide valuable additional information (9). Moreover, the Maharaj and Harding review (8) focused on the entire Caribbean region, and not specifically on the English-speaking Caribbean. The English-speaking Caribbean is comprised of 12 former British colonies that have ethnically diverse populations, that are connected culturally, and that share similar political and educational structures and socioeconomic links (10, 11). In addition, the 12 all have health structures based on a British colonial model, consisting of a centralized ministry of health and peripheral health facilities (12). Categorized as small island developing states (SIDS), these countries are a distinct group of developing nations facing specific social, economic, and environmental vulnerabilities related to size, geographically disparate populations, and limited health work forces (13). The Caribbean Public Health Agency (CARPHA) is the single common regional public health authority for the English-speaking Caribbean (14).

The objectives for our study were to comprehensively review literature on English-speaking Caribbean SIDS to identify the common themes documented in the literature on palliative and end-of-life care in those countries, and to describe what the barriers, improvement strategies, and suggested ways forward are.

MATERIALS AND METHODS

We chose a systematic scoping review because we wanted to broadly explore the subject of palliative and end-of-life care. Scoping involves the synthesis and analysis of a wide range of research and non-research material to provide greater conceptual clarity about a specific topic or field of evidence. In this way, scoping considers the breadth rather than the depth of evidence (15). This methodology is considered appropriate to gain information on a broad topic and rapidly map key concepts underpinning a research area, as well as the main sources and types of evidence available. It can be undertaken as a series of stand-alone projects, especially where an area is complex or has not been previously comprehensively reviewed (16).

Data collection

Our searches of the MEDLINE and Web of Science electronic databases incorporated broad search terms commonly used when searching for palliative care and conceptually related terminology. Medical Subject Headings (MeSH) words were used for MEDLINE (17), with the search string: ("Palliative Care"[MeSH]) OR "Terminal Care"[MeSH]) OR

"Terminally Ill"[MeSH]) OR "Medical Futility"[MeSH]) AND "Caribbean Region"[MeSH]). For the Web of Science, the Boolean search term “(palliative care OR terminal care OR terminal illness OR supportive care OR end-of-life care OR medical futility) AND Caribbean)” was used.

Additionally, we did a hand search of the references included in the selected publications and other relevant articles, such as policy reports. When a different database or information source was used, duplicate articles were removed by hand. No date restrictions on publications were used, but the search was conducted from June through November of 2015.

Data analysis

To obtain the relevant publications, three co-authors (NJ, KC, JC) reviewed the titles and abstracts, and applied the inclusion/exclusion criteria presented in Table 1.

To identify key issues surrounding palliative and end-of-life care in the English-speaking Caribbean, the Caribbean-based lead author (NJ) read completely and systematically categorized information obtained from the material included in the study. Two co-authors (KC and JC) additionally scanned the full texts of eligible articles to determine main themes and categories. Information was sifted, summarized, and later charted using a Microsoft Excel document developed for the process. For each publication, data were extracted on its title, main author’s country, publishing journal, year published, research design, and focus country or region. Emerging key issues were discussed by all co-authors during team meetings. Critical input on the developing manuscript came from a Caribbean-based researcher (CCM).

Table 1. Definition of terms and the inclusion and exclusion criteria for publications used for the systematic scoping review of palliative and end-of-life care in the English-speaking Caribbean, 2015

Category	Description
Definition of terms	"Palliative care" and "end-of-life care" are often used interchangeably, and we found publications that used the term "palliative care" that were not relevant to our study. Therefore, to standardize the decision for inclusion and exclusion of publications, the publications we selected had to fit the following definition of terms: • Palliative and hospice care, according to the WHO (2), are specific types of end-of-life care (not necessarily limited to the terminal phase) provided by health professionals and informal caregivers (volunteers and family carers). They include medical, psychological, and spiritual support, with the aim of helping people to achieve peace, comfort, and dignity in their final days, weeks, and months (1). • "End-of-life care" or "care at end of life" refers to all aspects of the care relating to dying, death, and bereavement that is provided toward the end of life. In this context, "end of life" can be from the point of receiving a life-limiting diagnosis through the months before death, up to and including the final hours—a continuum, rather than a point in time. We use "end-of-life care" to refer to the care of people with advanced life-limiting conditions, for whom death within one to two years is likely, as well as those in the terminal phase of illness. It also encompasses care of the bodily remains of the deceased person.
Inclusion criteria	The inclusion criteria were: • content that contained MeSH search terms that included: a) any of the English-speaking Caribbean countries and b) palliative and/or end-of-life care, terminal or supportive care, terminal illness, medical futility, or hospice care • written in English • were accessible via the Internet and/or in peer-reviewed journals, and were original papers, editorials, commentaries/ position papers, lectures, letters to the editor, or regional reports. • content specifically addressed one or more of the populations of independent English-speaking Caribbean nations (Antigua and Barbuda, the Bahamas, Barbados, Belize, Dominica, Grenada, Guyana, Jamaica, Saint Lucia, Saint Kitts and Nevis, Saint Vincent and the Grenadines, and Trinidad and Tobago)
Exclusion criteria	Articles that discussed palliation in a context other than end-of-life care, for example, the use of palliation as a corrective measure for surgical procedures

Source: Prepared by the authors using study data.

The data extraction step of the review facilitates inductive identification of commonalities and themes (16, 18). Consequently, we grouped our information into five main recurring themes. As we considered a description of the situation across each of the themes, it became apparent that barriers are often mentioned in relation to the current state of palliative care development, so we also mapped reasons for barriers and possible ways to reduce them.

RESULTS

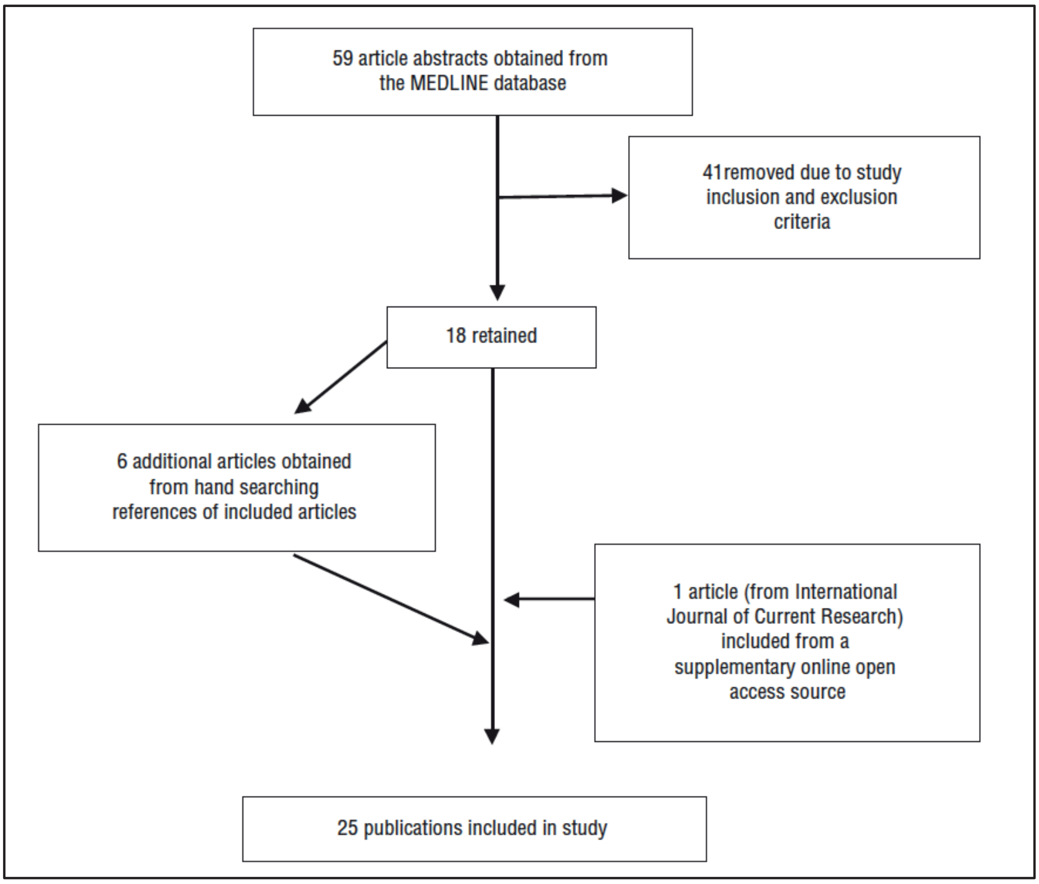
Search

MEDLINE yielded 59 article abstracts, with varying relevance to our aim (Figure 1). Of these, 18 were included in the study, plus an additional 7 after a hand search of the references included in the selected publications and supplemental online searches, for a total of 25 publications. The Web of Science database yielded 47 article abstracts, but none of them were new publications. The final 25 included articles from 1991 to 2015, and they had been published in 10 different journals (Table 2) (19-42). The first original studies, published in 2003, were from Grenada and Barbados. Other publications consisted of regional reports, commentaries/position papers, and editorials.

Five main themes

The review of the literature identifies five themes: 1) culture and attitudes of health care providers, patients, and those close to them towards illness death and dying; 2) access to and use of opioids for medical purposes; 3) development of services to complement palliative care capacity (education and training of health care professionals and care providers); 4) unmet palliative care needs (management of symptoms, financial burden, psychosocial burden borne by family caregivers, sickle cell anaemia patients and other marginalized groups) and 5) palliative care research.

FIGURE 1. Flow chart of included articles (N = 25) used for the systematic scoping review of palliative and end-of-life care in the English-speaking Caribbean, 2015[a]



Source: Prepared by the authors using study data.

[a] We also conducted a search in the Web of Science database, which yielded 47 article abstracts, but none of them were new publications not already found in the MEDLINE search.

Across the themes, the review also identifies barriers and suggest means of alleviating them. While themes, barriers, and solutions can overlap and are related culturally and socioeconomically, they are sufficiently distinct to be separated and examined. Due to limited data on palliative care in the English-speaking Caribbean, findings might relate to a specific country. However, the issues, circumstances, and challenges are likely to be similar in other countries of the region, due to their common history and shared cultural backgrounds.

TABLE 2. Characteristics of publications (N = 25) used for the systematic scoping review of palliative and end-of-life care in the English-speaking Caribbean, 2015

Characteristic	Category	No. of publications
Year of publication	2011 – 2015	8
	2006 – 2010	4
	2001 – 2005	8
	1996 – 2000	3
	1991 – 1995	2
Journals (N = 25)	Annals Of Oncology	3
	Cambridge Quarterly Of Healthcare Ethics	2
	Canadian Journal Of Anesthesia = Journal Canadien D'anesthésie	1
	Developing World Bioethics	1
	Geriatric Nursing (New York, New York)	2
	International Journal Of Current Research	1
	Journal Of Pain And Symptom Management	2
	Journal Of Palliative Medicine	3
	Public Library Of Science Medicine	1
	West Indian Medical Journal	9
Original studies' (n = 10) type of publication	Survey (19, 23, 36, 37))	4
	Bibliometric literature review (27)	1
	Cross-sectional mixed methods (22)	1
	Qualitative study/content analysis (24)	1
	Prospective quantitative study (34)	1
	Qualitative study/grounded theory (41)	1
	Mapping exercise (20)	1
Original studies (n = 10) country of origin	Jamaica	1
	Grenada	3
	Barbados	1
	Trinidad and Tobago	1
	Other	4
Original studies' (n = 10) population or topic of interest	Practicing clinicians working in the field of palliative care and/or cancer care (19, 37)	2
	Palliative care research (27)	1
	Cancer patients, their caregivers, health care providers, key informants and selected community members (22)	1
	Caregivers of persons who died within a designated timeframe (24)	1
	Patients admitted to a surgical Intensive Care Unit who later died (34)	1
	Health officials from 13 Caribbean Community and Common Market countries (23)	1
	Members of the Sickle Cell Association of Grenada ≥18 years old (36)	1
	Registered nurses who worked at a Trinidadian private hospital's Intensive Care Unit caring for paralysed patients (41)	1
	A global map and categorization of countries' overall state of palliative care practice and development (21)	1
Other materials' (n = 15) type of publication and country or organization of origin	Reports: PAHO (38, 43), GOPI (39), WHO (40), other (29)	5
	Journal editorials from Jamaican authors: (28, 32, 35, 42))	4
	Commentaries: Jamaica (21), Grenada (25), United States (30)	3
	Position paper: Grenada (26)	1
	Lecture to the Association of Surgeons of Jamaica: Jamaica (33)	1
	Letter to Journal editor: Jamaica/United States (31)	1

Source: Prepared by the authors using study data

An overview of the themes and corresponding issues is presented in online supplementary Table S1.

Theme 1: Culture and attitudes of health care providers, patients, and those close to them towards terminal illness and death

Historical ties to Europe and proximity to North America have encouraged the adoption of Western norms and values regarding lifestyles and taboos about death (21). The English-speaking Caribbean region's culture and attitudes are strongly shaped by religious beliefs that reinforce fatalistic attitudes and behaviours. For example, illnesses such as cancer are perceived as God-given punishment by some (22, 24), and pain is perceived by many as suffering that is unavoidable and unfortunate but part of God's overall plan. A historic norm is to expect and accept pain at the end of life (24-26). Mutual mistrust between healthcare practitioners and the public persists. Some members of the public believe that physicians are unwilling to be truthful when discussing negative diagnoses and terminal prognoses. The belief is, physicians avoid giving bad news believing that their patients will not be able to afford required medical treatments (22).

Reasons for these barriers. Options are either insufficient or lacking for patients and their families to obtain accurate and appropriate information about the trajectory of various cancers and terminal conditions, standards of medical care expected in wealthier nations, and psychosocial, financial, and educational support (22, 23). Poor communication between all parties hinders accurate information-sharing regarding illness, death, and dying (22, 34). An absence of or unfamiliarity with institutional and health system policy impinges on knowledge, attitudes, and practices regarding the prescription of opioids for pain (22, 25).

Possible ways to reduce these barriers. To address the needs of patients and their caregivers, a revision of government policy, education, and community-based care are recommended (22). Other recommendations include integrating palliative care into public health systems and improving analgesic availability and use (22, 24). Education campaigns can target policymakers and health care practitioners concerning pain management. Specifically, campaigns can target health care practitioners about improving their ability to communicate with patients, families, and caregivers (22, 24, 32). In addition, to dispel myths and misconceptions, the public can be educated about disease processes and available treatment options (22, 24). The development of broad-based multidisciplinary community-oriented palliative care programmes is also necessary (22, 24, 32).

Theme 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 low use (26). Limited hospital stocks of opioids contribute significantly to untreated medical pain (24, 25). 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 U.N. Human Development Index (20); other publications support this view (23, 37).

Reasons for these barriers. One of the primary impediments to effective pain relief is the absence of written national policies. Such documents can improve awareness among health practitioners, policymakers, and the public on the safety and efficacy of opioids (23-25, 37). A less visible barrier is the reluctance of pharmaceutical companies and importers to invest in the registration and promotion of products such as oral immediate-release morphine or oxycodone, which do not generate significant profit (19).

Possible ways to reduce these barriers. Health care professionals should follow the WHO's protocol for treating cancer pain (35), and the INCB suggests reforming restrictive government policy that hinders opiate availability (19, 37). Regulatory authorities should 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; and 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).

Theme 3: Development of services to complement palliative care capacity

Lynch et al. (20) mapped the global state of palliative care practice and development, placing countries into one of six categories. English-speaking Caribbean nations are in Groups 1, 2, and 3a. Group 1 (countries with no known hospice-palliative care activity) includes Antigua and Barbuda, Grenada, Saint Kitts and Nevis, and Saint Vincent and the Grenadines. Group 2 (countries with capacity-building activity) include the Bahamas and Dominica. Group 3a (isolated palliative care provision) includes 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).

Reasons for these barriers. As noted above, a nation's socioeconomic status and human development index correspond with the extent to which it provides palliative care, with a lower socioeconomic status impeding palliative care development (22-26, 35, 36, 39-42). This is reflected in English-speaking Caribbean nations, where socioeconomics limit the resources and infrastructure needed for providing palliative or hospice care at the standards expected in wealthy nations (23).

Possible ways to reduce these barriers. The WHO suggests countries adopt a public health approach outlined in its 2002 National Cancer Control Guidelines: (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). Other measures that may assist this process include government-stakeholder consultations that draw attention to the unique settings and needs of each country (26) and advocacy from ministries of health and PAHO on allocating necessary resources to implement decentralized palliative care programmes (43). Functions and resources of the private sector can be utilized to combat discrimination, prejudice, and ignorance about cancer and to provide informal psychosocial and spiritual counselling, bereavement support, and fundraising initiatives to assist households (22).

Theme 4: Unmet palliative care needs

Outside the hospital setting, there are few if any systems or resources for ongoing palliative or hospice care in the English-speaking Caribbean. Few medical and nursing staff are trained in how to provide pain relief. In addition, disease registries and palliative care services capable of providing ongoing emotional, spiritual, financial, and social support or training for family caregivers do not exist in many health systems and jurisdictions (22, 29). Needs of specific populations, such as persons living with HIV/AIDS or sickle cell disease, are often overlooked, and few medical or other support services are available (29, 36).

Reasons for these barriers. Crosscutting and converging issues related to resources (e.g., inadequate transportation to medical appointments) and infrastructure, as well as dysfunctional hierarchical relationships among health practitioners, contribute to unmet needs (23). Where palliative care services do exist, patients and the public are generally unaware of what they offer and how to access them (24).

Possible ways to reduce these barriers. Programmes involving a multidisciplinary team approach providing symptom management and psychosocial support for patients at home or in institutions can be developed and implemented (24). Examples likely to be effectively adapted to Caribbean socioeconomic and cultural contexts include effective pain relief (36) and sensitizing clinicians, administrators, and policymakers to the social services that patients and caregivers require (24).

Theme 5: Palliative care research

Investment in health research is limited in the Caribbean (22, 29, 41). Historically, health research in English-speaking Caribbean nations is underfunded; research agendas and research groups are lacking; and experienced researchers may often work in isolation, without a collaborative network (27).

Reasons for these barriers. In developing countries, palliative care is not recognized as a discipline, and national strategies do not encourage related research or integrate new findings into health systems. Most palliative care and related research journals are based in developed countries and are only accessible through individual or institutional subscriptions that are prohibitively expensive in many low- and middle-income countries (27).

Possible ways to reduce these barriers. The capacity for health research could be improved through medical curricula and/or continuing education programmes linked to the epidemiological and cultural contexts of the countries in the region. Strategies such as multidisciplinary palliative care research can stimulate collaboration among Caribbean researchers, and between researchers from developed and low- and middle-income countries. This process can facilitate a transfer of knowledge and may contribute to increased representation of Caribbean researchers on established editorial and research review boards (27).

DISCUSSION

This systematic scoping review identified five important themes among English-speaking Caribbean SIDS: 1) socioeconomic and cultural norms about terminal illness and death that influence the development and delivery of palliative and end-of-life care; 2) limited access to opioids for medical use; 3) limited palliative care services as compared to need; 4) unmet needs for palliative care; and 5) a lack of relevant research activity in the region.

This study is the first of its kind to comprehensively focus on and capture discussions in academic and grey literature surrounding palliative and end-of-life care specifically in the English-speaking Caribbean. A rigorous systematic process was used to extract core issues, and information was synthesized and presented as an overview in order elucidate the specific contexts, challenges, and possible solutions.

Limitations of this review relate to the limited volume of published literature—particularly original studies—on palliative and end-of-life care from or about the English-speaking Caribbean. There may be relevant articles besides the ones we found using our chosen search terms, databases, and hand searches. Likewise, the information we accessed may not capture all the relevant issues concerning palliative and end-of-life care in the region.

Findings from this study are not unique when compared to other developing countries in Latin America or Africa. In those areas, the most common issues appear to be that palliative care is not considered a public health priority, and that there is a lack of empirical information on the provision of and access to palliative care. Nevertheless, specific reasons exist for the lack of palliative care development in the Caribbean. An earlier review (8) that appraised the quality of nine original studies from the Caribbean found that the peer-reviewed literature provided only limited information on the need for palliative care in Caribbean populations. The study concluded that there are specific needs for palliative care policy, staff training, education, access to analgesia, and palliative care support services.

Our broader exploration of the available literature corroborates these conclusions. Including non-research material helps to clarify the complexity of core issues. For example, poor communication between all parties hinders accurate information sharing, and cultural taboos and attitudes of the public toward terminal illness and death are strongly influenced by religious beliefs. Also, when Caribbean countries offer a minimal level of universal health care, that contributes to unmet palliative care needs.

For palliative care to be effective, one of the main requirements is that the care be broadly accessible for persons in need (44). Our study has identified challenges as well as opportunities for improvement in the English-speaking Caribbean for the overlapping issues of practice, policy, and research. The pertinence of these public health challenges is greatly magnified, given the region’s context of aging societies faced with chronic and degenerative diseases.

Practice

Existing strengths and abilities may need to be further developed. For example, the Caribbean tradition of home care for the elderly (28) and the suggestion of community-based care units (21) can be expanded by involving religious and other community groups working within their respective neighbourhoods, and by training informal caregivers and community members in end-of-life caregiving. The Neighbourhood Network in Palliative Care in the Indian state of Kerala may be an example that, with the appropriate adaptation to the specific context, could meet the needs for and improve access to palliative care of different communities in low-resourced countries (45). Training community lay people can supplement health care services and deepen the reach of and broaden the coverage of palliative care services. Access to care can be increased by bringing services to individuals who need them. Inspired by the WHO’s concept of primary health care, the Kerala model appropriately addresses the challenge of increasing costs and commercialization of health care services in resource-poor regions.

Policy

Caribbean countries are faced with the absence of written national policies—combined with restrictive regulatory and legal procedures—on the medical use of opioid analgesics. Given this dilemma, Caribbean nations could be inspired by the example of how the country of Mongolia increased the medical use of opioids. In 2002, Mongolia was in its palliative care development infancy, with few analgesic drugs available (46). However, in less than five years, Mongolian stakeholders adopted and successfully implemented a strategy of using oncology services as a logical, humane, realistic, and cost-effective entry point for pain relief for a large percentage of those who needed palliative care (47). In addition, there is a vital need for an equity agenda if policies are to successfully reduce barriers for population health overall (48).

Research

Reliable studies to investigate the circumstances of dying and the needs for end-of-life care are a priority for developing palliative care in the English-speaking Caribbean. Pastrana et al. (7) noted that the clinical provision of care in low- and middle-income countries takes precedence over the development of palliative care research capacity. Further impeding research in resource-poor settings are such obstacles as limited institutional and regulatory frameworks, missing infrastructure, insufficient funding, and a shortage of qualified researchers. However, a viable strategy for establishing a research culture in English-speaking Caribbean countries might be integrating culturally relevant research methods into the existing curricula, while collaborating with foreign institutions capable of sharing their research expertise and infrastructure. Along with that, foreign benefactors could finance monitoring and evaluation activities (12). High-quality research is important and relevant because it can directly feed back into practice and policy by improving clinical skills training and by developing evidence-based health care interventions that are effective, feasible, and acceptable in resource-poor contexts.

Conclusions

This study highlights the need for palliative and end-of-life care in a distinct group of developing nations in the English-speaking Caribbean. The sparse literature available makes it challenging to gauge the magnitude of the problem. However, many of the primary impediments to developing palliative care in the region are clear: inadequate policy, medication, service development, and access to services, combined with a lack of research on palliative and end-of-life care.

The similarities between countries in the region can mean that progress on palliative care in one nation is used as a framework for intraregional development. Recognition of this by regional gatekeepers and policymakers may motivate them to invest in the necessary resources, structures, and initiatives that can propel the development of palliative and end-of-life care in the region.

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PART II USING AVAILABLE ADMINISTRATIVE AND ROUTINELY COLLECTED DATA TO DO POPULATION-LEVEL STUDIES IN RESOURCE-POOR CONTEXTS

3 Place Of Death In A Small Island State: A Death Certificate Population Study

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ABSTRACT

Objectives

Low/middle-income countries, particularly Small Island Developing States, face many challenges including providing good palliative care and choice in place of care and death, but evidence of the circumstances of dying to inform policy is often lacking. This study explores where people die in Trinidad and Tobago and examines and describes the factors associated with place of death.

Methods

A population-level analysis of routinely collected death certificate and supplementary health data where the unit of analysis was the recorded death. We followed the Reporting of Studies Conducted Using Observational Routinely Collected Health Data reporting guidelines, an extension of Strengthening the Reporting of Observational Studies in Epidemiology, on a deidentified data set on decedents (n=10 221) extracted from International Statistical Classification of Diseases version 10 coded death records for the most recent available year, 2010.

Results

Of all deaths, 55.4% occurred in a government hospital and 29.7% in a private home; 65.3% occurred in people aged 60 years and older. Cardiovascular disease (23.6%), malignancies (15.5%) and diabetes mellitus (14.7%) accounted for over half of all deaths. Dying at home becomes more likely with increasing age (70-89 years [OR 1.91, CI 1.73 to 2.10] and 90-highest [OR 3.63, CI 3.08 to 4.27]), and less likely for people with malignancies (OR 0.85, CI 0.74 to 0.97), cerebrovascular disease (OR 0.61, CI 0.51 to 0.72) and respiratory disease (OR 0.74, CI 0.59 to 0.91).

Conclusion

Place of death is influenced by age, sex, race/ethnicity, underlying cause of death and urbanisation. There is inequality between ethnic groups regarding place of care and death; availability, affordability and access to end-of-life care in different settings requires attention.

BACKGROUND

An understanding of where people die is fundamental to policy planning and to improving care towards the end of life; it will provide insight into the different needs of diverse populations requiring care like older people or those with terminal cancer, and suggest how care can be made available, affordable and appropriate.[1] Enabling choice about place of care and death is one of the main aims of palliative care and has important implications for the dying process. If quality of care is not compromised, the home environment is often the preferred place of death (POD)[2,3] since it is associated with a better quality of dying, that is, with dignity and autonomy[4] and greater involvement of family and informal caregivers.[5] However, hospital remains the most common place,[1,6] which may be related to the limited access to and provision of home-based care, the burden on family caregivers and the convention that institutional care is better at addressing the complex needs of people at the end of life.[7]

POD at a population level is related to healthcare expenditure,[8] end-of-life care policy,[9] and palliative care development.[10] Despite increasing concern about the high disease burden from HIV and AIDS,[11] cancer and chronic diseases[12] that can significantly contribute to palliative care needs,[10] palliative care development in the developing world remains at dramatically low levels.[13] The World Health Organisation acknowledges the existence of a palliative care needs gap in developing countries[14] and, at the population level, the delivery of care with a focus on improving the circumstances and quality of death – specifically choice about POD[3] – is now a major public health challenge.[15]

This challenge extends to English-speaking Caribbean, Small Island Developing States (SIDS), a unique group of developing countries with similar developmental constraints.[16] They are relatively small with limited natural resources and small economies which leads to dependence on external finance, their small populations limits; their human resources, employment opportunities and social and healthcare services.[17] The case for Trinidad and Tobago (T&T), a twin island republic located in the southern Caribbean (Table 1).[18-22] In this context, T&T has gone from having mainly communicable to non-communicable disease, and now has among the highest morbidity and mortality rates for chronic non-communicable diseases (heart disease, stroke, diabetes and cancer) in the Caribbean.[23]

Table 1. Fact sheet for Trinidad and Tobago

Feature	Value
Country size (sq. km)*	Total: 5128 Trinidad: 4828 Tobago: 300
Total Population (2011)*	1,328,019
Life expectancy (2013) by sex†	Female: 74 years Male: 66 years
Ethnic composition (2011, by %)*	East Indian – 35.4 African – 34.2 Mixed – 22.8 White – 0.6 Chinese – 0.3 Other – 6.7
Medical opioid consumption (2013) ‡	1–10 mg morphine equivalents/capita /year
Public expenditure on health care (2010)§	3.7 Billion TTD
Health expenditure as percentage of Gross Domestic Product (2010)¶	5.1%

*** 2011 population and housing census demographic report [18]**
† Pan American Health Organisation, Health Situation in the Americas, Basic Indicators 2013 [19]
‡ The Global Opioid Policy Initiative[20]
§ Ministry of Health Statistical Report 2009 – 2011[21]
¶ World Health Organisation Global Health Observatory data repository, 2016 [22]
Abbreviations – TTD: Trinidad and Tobago dollar (1 U.S. dollar = 6.30TTD)

In 2015, 14.2% of the population was 60 years and older and is expected to increase to 20.2% and 28.2% by 2030 and 2050 respectively. Life expectancy is also projected to increase over this period.[24] However, the development of palliative care practice is not in line with these changes in population demographics. When described in comparison to a global categorization of countries, palliative care in T&T is ‘Isolated Palliative Care Provision’ – meaning that a national commitment to palliative care practice is absent and what exists is lacking in scope and focused governmental, social and financial support, for example, unreliable availability of morphine at the nation’s health institutions and a small number of hospice and palliative care services in relation to population size. Other Caribbean countries included in this category are Barbados, Belize, Guyana, Jamaica and Saint Lucia.[25] In T&T there are three in-patient services – one government operated palliative care unit and two non-governmental hospice programmes, two community palliative care services including one in Tobago, an out-patient clinic at a government hospital and a consulting service provided by the government operated palliative care unit. For low-resourced countries like SIDS, with an absence of data on where people prefer to receive end-of-life care and where they wish to die, using routinely collected data - generated by administrative and clinical processes rather than specially for the purposes of research[26] – is useful and cost-effective for studying POD and circumstances of dying.[27,28] This population-level study is aimed at exploring where people die in T&T and examining and describing the factors associated with their POD.

METHODS

Design

In 2017, we conducted a population-level analysis of routinely collected death certificate and supplementary health data; the unit of analysis was the recorded death in T&T. We followed the Reporting of Studies Conducted Using Observational Routinely Collected Health Data reporting guidelines[29] an extension of Strengthening the Reporting of Observational Studies in Epidemiology, on a deidentified data set on decedents (n = 10,221) extracted from International Statistical Classification of Diseases version 10 (ICD-10) coded death records for the most recent available year, 2010.

Setting and population

A dataset on all deaths, residents and visitors, (n = 10,221) that occurred in T&T in 2010, the most recent available year, was obtained from the T&T national death registry, the Central Statistical Office (CSO). The dataset contained deidentified death records extracted from 10 (ICD-10) coded death certificates. In T&T physicians complete the medical certificate of cause of death (Appendix 1) and the CSO processes the data into a registry. The CSO provided supplementary census data (community classification of urbanisation), and data on percent of the population living in an urban setting in 2010 (9.1) was obtained from the World Health Organisation.[30] The Ministry of Health provided health resource data, that is, the number of government hospital beds *(*n = 2,009) and the proportion of beds per Regional Health Authority (RHA). The five RHAs, North-West, North-Central, South-West, Eastern and Tobago, provide health services to the general public.

Measures

The dependent variable, POD, was categorised as: private home, government hospital, nursing home or non-government hospital and other (for example, public places, workplaces, roads and private geriatric homes). Independent variables included: age at death, sex, ICD-10 coded cause of death. We followed the CSO's usage of terms for race/ethnicity (East Indian, black, mixed, white and Chinese), level of urbanisation (categorised as urban and rural in Trinidad and semi-urban added in Tobago), and the number of government hospital beds available in 2010. Government 'hospital bed availability per 10 deaths' figures were derived from the latter variable and calculated according to the five RHAs and linked to the municipality of residence of the deceased. The number of beds at the only psychiatric hospital located in the North-West RHA were excluded.

Statistical analysis

Distribution for POD was described using frequency analysis. Two multivariable binary logistic regression analyses were performed to determine the association between POD and various covariates known to be associated with it. Home vs other and government hospital vs other were used as dependent variables. Independent variables entered into the regression model are: age (0-17, 18-69, 70-89, 90-highest), cause of death, which was condensed into categories potentially requiring palliative care according to prior research (malignancies, diseases of the nervous system, diabetes mellitus, cardiovascular disease, cerebrovascular disease, and respiratory disease,[31] and all other causes), RHA of residence and urbanicity of the municipality of residence. Covariates were considered significant if the P value was <0.05. The categories, nursing homes and non-government hospitals could not be differentiated from one another but were used in analyses along with 'other' POD. As 61.1% of data were missing for the variable race/ethnicity it was not included in the main regression analysis. However, a separate regression model was tested to evaluate whether any differences existed between ethnic groups and POD, taking into account the influence of confounding factors. A separate analysis was also performed with 'hospital beds per 10 deaths' as an independent variable instead of RHA of residence to evaluate the influence of hospital bed availability on POD. All statistical analyses were done using SPSS V.24.

RESULTS

The mean age at death was 63.7 years (median 68). The majority of deaths (65.3%) occurred aged 60 and older; more males (57%) than females died, and cardiovascular disease (23.6%), malignancies (15.5%) and diabetes mellitus (14.7%) accounted for over half of all deaths

(Table 2). Overall, the largest proportion of deaths (55.4%) occurred in a government hospital; 29.7% occurred at home and 5.9% in a nursing home/non-government hospital (Table 3). The younger the decedent group, the higher the proportion who died in government hospitals. POD of people categorised as ethnically white is different from every other race/ethnic group; about half (48.8%) died at home and 17.1% in a nursing home or non-government (private) hospital, more than any other ethnic group, whereas 29.3% died at a government hospital, the least of any other group. A higher proportion of those dying from diseases of the nervous system (43.4%) died at home, more than any other disease group.

Table 2. Demographic characteristics of all registered deaths in 2010 (N=10,221)

	Frequency	**Percentage (%)**
Deceased Age		
< 1	258	2.5
1 thru 17	126	1.2
18 thru 59	3145	30.8
60 thru 69	1856	18.2
70 thru 79	2085	20.4
80 thru 89	1961	19.2
90 thru highest	773	7.6
Decease Sex		
Male	5822	57
Female	4398	43
Cause of Death		
Malignancies	1579	15.5
Non-malignant neoplasms	71	0.7
Nervous system disease	248	2.5
Diabetes mellitus	1505	14.7
Cardiovascular disease	2409	23.6
Cerebrovascular disease	920	9.0
Respiratory diseases	502	4.9
Liver and kidney disease	245	2.4
Human immunodeficiency virus (HIV) disease	226	2.2
External cause of death	956	9.4
Suicide	160	1.6
Other cause of death	1400	13.7

The comparatively rural Eastern RHA registered the smallest proportion of deaths (10.6%) but the places of death approximated the other RHAs, whilst the South-West region registered the largest proportion (33.9%) (Appendix 2).

Table 3. Demographic, health resource and supplemental characteristics of all registered deaths in relation to the place of death (2010)

	Private Home n †(%)	Government Hospital n (%)	Nursing Home and Non-government Hospital n (%)	*Other n (%)
All deaths	3031 (29.7)	5662 (55.4)	606 (5.9)	921 (9.0)
Sex				
Male	1663 (28.6)	3192 (54.8)	300 (5.2)	667 (11.5)
Female	1368 (31.1)	2470 (56.2)	306 (7.0)	254 (5.8)
Age				
< 1	7 (2.7)	239 (92.6)	8 (3.1)	4 (1.6)
1 – 17	17 (13.5)	74 (58.7)	10 (7.9)	25 (19.8)
18 – 59	608 (19.3)	1889 (60.1)	123 (3.9)	525 (16.7)
60 – 69	515 (27.7)	1139 (61.4)	94 (5.1)	108 (5.8)
70 – 79	702 (33.7)	1172 (56.2)	128 (6.1)	83 (4.0)
80 – 89	791 (40.3)	915 (46.7)	154 (7.9)	101 (5.2)
> 90	390 (50.5)	228 (29.5)	89 (11.5)	66 (8.5)
‡Race/ethnicity				
East Indian	538 (31.0)	1046 (60.4)	77 (4.4)	72 (4.2)
Black	432 (24.9)	1152 (66.5)	72 (4.2)	77 (4.4)
Mixed	124 (30.0)	233 (56.4)	28 (6.8)	28 (6.8)
White	20 (48.8)	12 (29.3)	7 (17.1)	2 (4.9)
Chinese	14 (28.0)	27 (54.0)	5 (10.0)	4 (8.0)
Cause of death				
Malignancies	492 (31.2)	863 (54.7)	90 (5.7)	134 (8.5)
Diseases of the nervous system	98 (43.4)	85 (37.6)	25 (11.1)	18 (8.0)
Diabetes mellitus	523 (34.8)	834 (55.4)	100 (6.6)	48 (3.2)
Cardiovascular disease	920 (38.2)	1231 (51.1)	150 (6.2)	108 (4.5)
Cerebrovascular disease	264 (28.7)	547 (59.5)	79 (8.6)	30 (3.3)
Respiratory disease	157 (31.3)	283 (56.4)	40 (8.0)	22 (4.4)
Other	577 (24.0)	1819 (57.9)	122 (4.8)	561 (13.3)
Regional Health Authority				
North West	707 (26.1)	1507 (55.7)	176 (6.5)	316 (11.7)
North Central	746 (29.7)	1383 (55.0)	164 (6.5)	222 (8.8)
South West	1121 (32.7)	1911 (55.8)	187 (5.5)	206 (6.0)
Eastern	349 (32.5)	564 (52.5)	51 (4.7)	110 (10.2)
Tobago	100 (26.7)	227 (60.5)	19 (5.1)	29 (7.7)
Level of urbanisation				
Urban	1736 (27.2)	3630 (56.8)	430 (6.7)	597 (9.3)
§Semi-urban	34 (28.3)	71 (59.2)	4 (3.3)	11 (9.2)
Rural	1253 (35.0)	1891 (52.8)	163 (4.6)	275 (7.7)

***Public places, workplaces, roads etc. †Presented percentages are row percentages. ‡61.1% of data were missing for the variable race/ethnicity. §Semi-urban used only in Tobago**

A stepwise logistic regression model controlling simultaneously for the effects of different covariates identified age, cause of death, urbanisation, sex and RHA as predictors of dying at home (vs elsewhere) and of dying in hospital (vs elsewhere) (Table 4).

Table 4. Logistic regression for deaths at home and government hospitals in relation to demographic and healthcare characteristics (2010)

	home deaths vs elsewhere		**government hospital deaths vs elsewhere**	
Characteristics	**OR**	**CI (95%)**	**OR**	**CI (95%)**
Sex				
Male	–	–	0.87	0.80 – 0.94
Female	1	1	1	1
Age				
0 – 17	0.30	0.20 – 0.46	2.67	2.03 – 3.50
18 – 69	1	1	1	1
70 – 89	1.91	1.73 – 2.10	0.66	0.60 – 0.72
90 – highest	3.63	3.08 – 4.27	0.25	0.21 – 0.30
Cause of death				
Malignancies	0.85	0.74 – 0.97	–	–
Diseases of the nervous	1.44	1.08 – 1.93	0.49	0.37 – 0.66
system	–	–	–	–
Diabetes mellitus	1	1	1	1
Cardiovascular disease	0.61	0.51 – 0.72	1.46	1.25 – 1.71
Cerebrovascular disease	0.74	0.59 – 0.91	1.27	1.04 – 1.55
Respiratory disease	0.50	0.44 – 0.56	–	–
Other				
Regional Health Authority				
North West	1	1	1	1
North Central	1.17	1.03 – 1.34	–	–
South West	–	–	–	–
Eastern	–	–	–	–
Tobago	–	–	1.41	1.07 – 1.86
Urbanisation				
Urban	1	1	1	1
Semi-urban	–	–	–	–
Rural	1.51	1.35 – 1.70	0.77	0.69 – 0.86

Stepwise logistic regression controlling for sex, age, cause of death, regional health authority and urbanisation. 1 = reference variable

Dying at home becomes more likely with increasing age. Compared with those aged 18-69 it is more likely at age 70-89 (OR 1.91, CI 1.73 to 2.10) and age 90-highest (OR 3.63, CI 3.08 to 4.27). Home death was also more likely for those with diseases of the nervous system (OR 1.44, CI 1.08 to 1.93) compared with the reference group, people dying from cardiovascular diseases, but less likely for people with malignancies (OR 0.85, CI 0.74 to 0.97) cerebrovascular disease (OR 0.61, CI 0.51 to 0.72) or respiratory disease (OR 0.74, CI 0.59 to 0.91) than the reference group. Dying from diseases of the nervous system (OR 0.49, CI 0.37 to 0.66) was associated with a lower chance of dying in hospital. Although the Eastern RHA covers the largest geographic area, it has the lowest population density in Trinidad, and between RHAs there is little difference in chances of dying at home or in hospital. Compared with the North-West RHA, there is a slightly higher likelihood of home death (OR 1.17, CI 1.03 to 1.34) in the North-Central RHA, and a slightly higher likelihood of hospital death (OR 1.41, CI 1.07 to 1.86) for those in the Tobago RHA. Living in a rural area is associated with a higher likelihood of dying at home (OR 1.51, CI 1.35 to 1.70) and a lower likelihood of dying in hospital (OR 0.77, CI 0.69 to 0.86).

A multivariable logistic regression model where the 'number of hospital beds per 10 deaths' within an RHA was entered as a continuous variable instead of the RHA variable itself, controlling for sex, age, cause of death and urbanisation, did not reveal a significant association between the number of hospital beds and the chance of dying in hospital versus home (Supplemental 2). A regression model with the variable race/ethnicity (61.1% of data were missing) as an independent variable, controlling for age, sex and cause of death, confirmed a significantly lower chance of dying at home for black (OR 0.51, CI 0.27 to 0.98) than for ethnically white people and a larger chance of dying in hospital for East Indian (OR 2.32, CI 1.14 to 4.71) and black (OR 3.33, CI 1.64 to 6.74) compared with ethnically white people (Supplemental 3).

DISCUSSION

Main findings

This study provides a population distribution for POD in T&T in 2010. More than half - 55.4% - of deaths occurred in a government hospital and less than a third - 29.7% - in a private home. Dying at home was associated with increasing age; hospital deaths were more associated with cerebrovascular and respiratory diseases as underlying cause of death. Of all deaths, two thirds were in an urban setting and approximately one third - 33.9% - occurred in the South-West RHA. However, there were no significant differences between RHAs and POD. Individuals dying of conditions associated with the need for palliative care – chronic disease and cancer – conditions that can be an indicator of palliative care performance, were less likely to die at home. An important finding for policy and practice.

Strengths & Limitations

This study demonstrates that even in low-resourced environments like SIDS, it may be possible to use death certificate and supplementary health data to study POD. Completed death certificates are a useful tool to assess national mortality as patterns are described within the whole population.[32] Data from death certificates are widely used as information sources for epidemiologic studies, and generally, routinely collected data - death certificate and health resource - can be an available secondary and low-cost source for researchers, although they too have their limitations. There are inaccuracies in recording cause of death[27] and issues regarding completeness, for example, race/ethnicity in death certificates.[33] On the T&T death certificate, options for selecting POD are restricted to four categories, and groups together very diverse places, that is, nursing homes, private hospitals, hospices and geriatric homes. Moreover, in many countries where POD is registered, demographic data like marital status, income bracket or educational level are considered as relevant determinants, [27] but this information is not collected in T&T. And the inability to link sociodemographic data from a national census to death certificates can limit the depth of this kind of research.[34]

INTERPRETATION

To date, no large-scale robust palliative care studies have been done in T&T and literature is lacking. Our analysis of 2010 data is relevant as a starting point to enable exploration of POD and its associated factors. A possible explanation for the most common POD, government hospitals, could be a reliance on institutionalised care, since T&T has a public healthcare system that is free of charge at the point of delivery. The high prevalence of non-communicable diseases and related morbidity, along with the convention that institutional professional care is better at coping with the complex range of symptoms and needs, as opposed to the availability of primary care alternatives offered by general practitioners,[12] might further explain the high number of hospital deaths. More importantly, hospital deaths may reflect the slow development of palliative care policy and services at home.[25] The lack of alternatives like home-based, community or hospice care may be driving people into government hospitals. This is more obvious in Tobago, which has a greater proportion of hospital deaths than Trinidad, which suggests fewer alternatives for place of care and death than Trinidad.

The proportion of home deaths found in T&T is substantially lower than in developed countries such as Italy and the Netherlands but is in line with that found in other countries such as England and Wales (2008) and Belgium (2005-07) which have invested in the availability of quality end-of-life care outside the home[1] and in enabling a death at home if people prefer. [4,27,28] It could be that home deaths in T&T are due to Caribbean cultural traditions, family expectations and religious beliefs about caring at home for older people, the differently abled or terminally ill[35] as opposed to people choosing to die at home or receiving palliative care at home. This potential cultural influence is corroborated by the finding that older people are more likely to die at home but without government services like medical and nursing care or pain relief, as well as without financial and social support, including training for informal home care providers.[35,36]

Interestingly, similarities with dying at home are apparent between T&T and countries such as France, Italy, Spain, England, New Zealand, the USA and Mexico, where home deaths are more likely among women and those living in rural areas.[2] In T&T, it could be that women are less inclined to receiving aggressive treatment at the end of life and more likely to remain and die in their usual place of residence.[37] Those living in rural areas may choose to be cared for and die at home because of longer distances and travel time to hospitals or specialised end-of-life care settings like hospices;[28] impeded not by impassable mountain ranges but by poorly maintained and congested secondary roads and a lack of reliable transport services.

Considering that the majority of people who die with serious health-related suffering associated with a need for palliative care and pain relief live in developing countries,[13] there may be a need in T&T to encourage different place of care and POD trajectories than what was observed in the data. For example, initiating palliative care upon a diagnosis of a life-threatening illness may substantively direct where care is provided and allow choice for the place of death. The discrepancy between ethnic groups in POD is noticeable, although the data must be interpreted with caution as information on race/ethnicity was often missing. The largest difference was found between ethnically white people, who have the highest chances of dying at home, and ethnically black people, who have the lowest. Lower income is considered a determinant of hospital death.[38] If we consider socioeconomics as a proxy between these groups, with ethnically black people generally having a lower disposable income than ethnically white people,[39] and less access to scarce home care services or care outside government hospitals, then this observation supports the conclusion that people with higher incomes were more likely not to die in a government hospital.

It cannot be excluded, of course, that cultural preferences and expectations differ between ethnic groups.[40] This inequality in end-of-life care and POD requires further attention from national policy and healthcare planners. For example, if ethnic group disparities are due to geographical clustering then geographical planning of services may address this issue. And, if disparities are due to a difference in culture between ethnic groups, then policy can focus on public education campaigns that emphasise dispelling myths and misconceptions about disease processes, available treatment options and access to alternatives to hospital care like home or community-based care.[36] This study provides a clear analysis model for POD in low-resourced contexts like SIDS, and POD patterns allow for projections of public health policy by identifying which care settings require attention and how best to provide appropriate care.[2] A major challenge for T&T, with an aging population afflicted with cancer and chronic disease, is how to identify people who can benefit from palliative care and how to improve coverage and necessary programmes to a growing target population.[41] The numbers apparently seeking care at the end of life and subsequently dying in government hospitals may prompt policy makers to debate a need to increase the number of hospital beds to meet increasing demand.

A small country like T&T may not be able to sustain the economic burden this can pose. Of course, much more research is required to explore these issues to get a better understanding of palliative care need and how best to address this need, for example, exploratory studies about what triggers hospitalization in T&T and what quality of end-of-life care people receive. To decrease hospital expenditure, many European countries have adopted policies and strategies to reduce the number of people dying in hospitals,[32] beyond just a reduction in the number of hospital beds. Our findings corroborate those from previous studies showing that fewer hospital beds does not necessarily translate into fewer people dying in hospital.[42,43] A

Swedish study found that older individuals living in areas with a lower number of hospital and nursing home beds were more likely to die in hospitals or nursing homes compared with those in regions with higher numbers of beds.[42] It appears that the availability of alternatives to hospitals, like home care and geriatric homes, and how care is integrated, plays a much more important role than the availability of hospital beds in influencing POD patterns.[43]

CONCLUSION

In T&T, POD is influenced by age, sex, race/ethnicity, underlying cause of death and urbanisation. The number of government hospital beds within and between RHAs have little influence on deaths in government hospitals versus private homes. For POD, the most common places to die are government hospitals and a majority of these deaths are indicative of palliative care need. Home death is more common for older people, but the chances of home death are particularly lower for younger people or people in Tobago. An obvious difference in POD between race/ethnic groups suggests potential inequality regarding availability, affordability, and access to end-of life care across all care settings. Preference for POD is unknown, and if home care is not a culturally or financially viable option then policy can focus on developing palliative care units in each hospital or on other alternatives like community care. A better understanding is needed of the socio-demographics of the POD, and services should focus on offering options and choice for place of care and death.

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4 Trends In Place Of Death In A Small Developing Country: A Population-Level Study Using Death Certificate Data

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ABSTRACT

Background

Valuable information for planning future end-of-life care services and care facilities can be gained by studying trends in place of death. Scarce data exists on place of death in small developing countries. This study aims to examine shifts in the place of death of all persons dying between 1999 thru 2010 in Trinidad and Tobago, to draw conclusions about changes in the distribution of place of death over time, and the possible implications for end-of-life care practice and policy.

Methods

A population-level analysis of routinely collected death certificate data of the most recent available fully coded years at the time of the study–1999 to 2010. Observed proportions for place of death of all deaths were standardized according to the age, sex and cause of death distribution in 1999. Trends for a subgroup of persons who died from causes indicative of a palliative care need were also examined.

Results

The proportion of deaths in government hospitals increased from 48.9% to 55.4% and decreased from 38.7% to 29.7% at private homes. There was little variation between observed and standardised rates. The decrease in home deaths was stronger when the palliative care subcategory was considered, most notably from cancer.

Conclusion

Internationally, the proportion of deaths at institutions is increasing. A national strategy on palliative and end-of-life care is needed to facilitate the increasing number of people who seek end-of-life care at government hospitals in Trinidad and Tobago, including an investigation into the reasons for the trend. Alternatives to accommodate out-of-hospital deaths can be considered.

INTRODUCTION

Place of death (POD) has become an important aspect of quality end-of-life care (EOLC)[1] and having choice in the place we die is associated with human dignity.[2-4] In countries with developed palliative and EOLC services, dying in an acute hospital is viewed negatively.[5] To optimize dignity in dying,[6] some of the most prominent efforts to improve EOLC, such as hospices and palliative care services, are meant to facilitate death at home or in homelike surroundings.[7,8] The place where people die also has important consequences for healthcare costs, as EOLC in hospitals has been demonstrated to be more expensive than out-of-hospital care.[9] Therefore, studying trends in POD is important as changes can be detected and evaluated to understand why they occur. This has relevance in planning of future EOLC services and care facilities and can relate to policies around access, availability, affordability and quality of care in different settings.[8]

Trinidad and Tobago (T&T) is a low-resourced, Caribbean, Small Island Developing State (SIDS), a group of developing countries susceptible to vulnerabilities including: their geographic position, e.g., remote locations with limited access by international travel connections; economic e.g., small populations dependent on a narrow range of exports and limited access to affordable international finance;[10] and healthcare related e.g., there are limited specialized health professionals and associated infrastructure and palliative care (PC) is not integrated into healthcare systems.[9] A national commitment to PC practice is absent and existing services lacks scope and governmental support, this level of PC development is considered 'isolated'.[11] However, in addition to two private hospices, more recent developments include: the establishing of a national PC society in 2011, a government operated PC unit offering a consulting service, a government out-patient and small community services.

The population is aging: in 2015 14.2% of the population was 60 years and older and this figure is expected to increase to 20.2% by 2030; the total population as well as life expectancy are also projected to increase over this period.[12] Moreover, T&T has among the highest morbidity and mortality rates in the Caribbean for chronic diseases like; heart disease, stroke, diabetes mellitus and cancer,[13] medical conditions indicative of PC needs.[14] Yet, little is known about POD in relation to palliative and EOLC in T&T, as the topic is under researched, and no information exists on the preferred POD of patients with terminal illnesses, e.g., private homes, government hospitals, private nursing homes or geriatric care homes. However, a recent study that investigated all deaths that occurred in 2010 showed that POD is influenced by age, sex, race/ethnicity, underlying cause of death and level of urbanisation. Most deaths, 55.4%, occurred in a government hospital and 29.7% in a private home, dying at home was more likely with increasing age, and government hospital deaths were more associated with cerebrovascular and respiratory diseases as the underlying cause of death.[15] Despite these important insights, trends of where people die and why they die where they do over the past decades have not been studied. By examining trends in the circumstances of death and dying including for a subgroup of the population likely to need PC creates substantial knowledge in understanding some of the societal challenges regarding EOLC in T&T.

Studies that have considered POD trends have done so in relation to shifts in the age, sex and underlying cause of death of the population,[16-18] and in the context of T&T, studying similar trends in POD allows for cross-national comparisons, but more importantly, focuses attention on what impact an aging population with high morbidity and mortality from chronic non-communicable diseases can have on a low-resourced country with underdeveloped palliative and EOLC practices and services. The aims of this study are to examine trends in the place of death; by age, sex and cause of death, of all persons dying between 1999 thru 2010 in a small developing country, to draw conclusions about changes in the distribution of POD over time, to consider a sub-category of persons who died from some of the most common chronic life-limiting conditions indicative of a PC need, and to identify implications for EOLC and policy practice related to trends.

METHODS

Design

This is a population-level analysis of routinely collected death certificate data, the unit of analysis was the recorded death as medical death certificates contain sociodemographic information of the decedent. We followed the REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) reporting guidelines.[19]

Setting and population

The study was done in 2018 and due to coding delays, fully completed and reliable datasets were only available for the years 1999 thru 2010. They were obtained from the Central Statistical Office (CSO), the agency that processes the national mortality database from medical death certificates and compiles this data into a registry. Demographic characteristics of decedents, residents and visitors (N=118,703), including the year and place of death, age, gender and main underlying cause of death were extracted from the records. Data were de-identified and ethics approval was not necessary as per T&T regulations.

Measures

The dependent variable is the place of death (POD). We followed the categorisation for POD from the medical certificate of death, which is grouped according to the following four categories: private home, government hospital (including psychiatric units), nursing home or non-government hospital (both are private institutions with beds, nursing or convalescent homes can provide intermediate care, whereas non-governmental or private hospitals are equipped with accident and emergency rooms and can provide a full range of medical services), and other (inclusive of private geriatric homes, public places and leisure facilities, workplaces, and roads). Independent variables are, the year of death (1999-2010), age at death, sex and the underlying cause of death coded using the International Statistical Classification of Diseases version 10 (ICD-10). A sub-category of persons who died from some of the most common chronic life-limiting conditions in T&T that are indicative of a PC need were considered in analysis. These included the following diseases and their corresponding ICD10 coding: cardiovascular disease (I00 – I52, I70 – I99), malignancies (C00 – C97), respiratory disease (J00 – J99), diseases of the nervous system (G00 – G99), cerebrovascular disease (I60 – I69), and diabetes mellitus (E08 – E13). All remaining causes were grouped into the category other.

Statistical analysis

We calculated observed annual percent changes in the POD proportions and patterns over time that were described using cross-tabulations and frequency analysis with the independent variables. Trends in POD could be the result of shifts in the age, sex and cause of death distributions of the population over time, therefore, the POD rates were standardized using the 1999 population as the standard population. Age at death that was grouped into the following categories (0-59, 60-69, 70-79, 80-89 and 90 years or more), sex (male or female), and cause of death. As such temporal comparisons of POD can be done which are unaffected by changes in the socio-demographic or disease-related composition of the dying population. As the data are population-level data, no tests for statistical significance were performed. POD trend differences were analysed and described using temporal frequency comparisons of the observed and the standardised rates. All statistical analyses were done using SPSS 25 and Microsoft Excel for the standardization.

RESULTS

From 1999 to 2010, the total number of observed deaths was 118,703 (Table 1).

Table 1. Deaths from 1999 thru 2010 in Trinidad and Tobago by sex, age, and cause of death

	Years											
	1999	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**
All deaths (N)	10014	9479	9753	9797	10206	9872	9885	9668	9654	10463	9693	10219
Sex												
Male	55.2%	55.6%	56.2%	56.8%	56.9%	56.8%	57.7%	56.5%	56.7%	57.4%	57.2%	57.0%
Female	44.8%	44.4%	43.8%	43.2%	43.1%	43.2%	42.3%	43.5%	43.3%	42.6%	42.8%	43.0%
Age												
0 thru 59	36.3%	38.8%	38.1%	37.7%	37.4%	36.5%	36.9%	36.5%	36.9%	36.7%	37.8%	34.6%
60 thru 69	17.6%	17.3%	16.9%	16.9%	16.5%	17.9%	17.8%	17.4%	17.3%	17.5%	17.7%	18.2%
70 thru 79	22.1%	21.5%	21.1%	21.1%	21.2%	20.3%	20.1%	20.4%	20.7%	20.2%	19.7%	20.4%
80 thru 89	18.2%	16.8%	17.5%	17.6%	18.5%	18.8%	18.2%	18.7%	18.0%	18.1%	17.4%	19.2%
90 thru highest	5.8%	5.6%	6.3%	6.7%	6.4%	6.5%	7.0%	7.0%	7.0%	7.5%	7.4%	7.6%
Cause of death												
Cardiovascular disease	28.2%	27.1%	26.6%	26.3%	26.2%	26.0%	25.6%	26.1%	24.4%	24.6%	24.3%	23.6%
Malignancies	12.6%	12.7%	12.4%	13.0%	13.0%	13.7%	13.8%	13.7%	14.6%	13.6%	14.3%	15.5%
Respiratory disease	5.5%	4.1%	3.9%	4.9%	5.5%	5.5%	5.1%	4.8%	4.8%	5.2%	5.1%	4.9%
Diseases of the nervous system	1.7%	2.0%	1.7%	2.0%	2.1%	1.9%	2.2%	2.2%	2.3%	2.0%	2.3%	2.2%
Cerebrovascular disease	10.4%	10.1%	10.0%	10.4%	10.0%	9.6%	9.1%	9.0%	8.8%	8.0%	8.7%	9.0%
Diabetes mellitus	13.0%	13.6%	13.7%	13.0%	14.0%	13.9%	14.1%	13.6%	14.3%	13.6%	13.9%	14.7%
Other	28.5%	30.5%	31.7%	30.4%	29.2%	29.2%	30.1%	30.5%	30.7%	33.0%	31.3%	30.1%

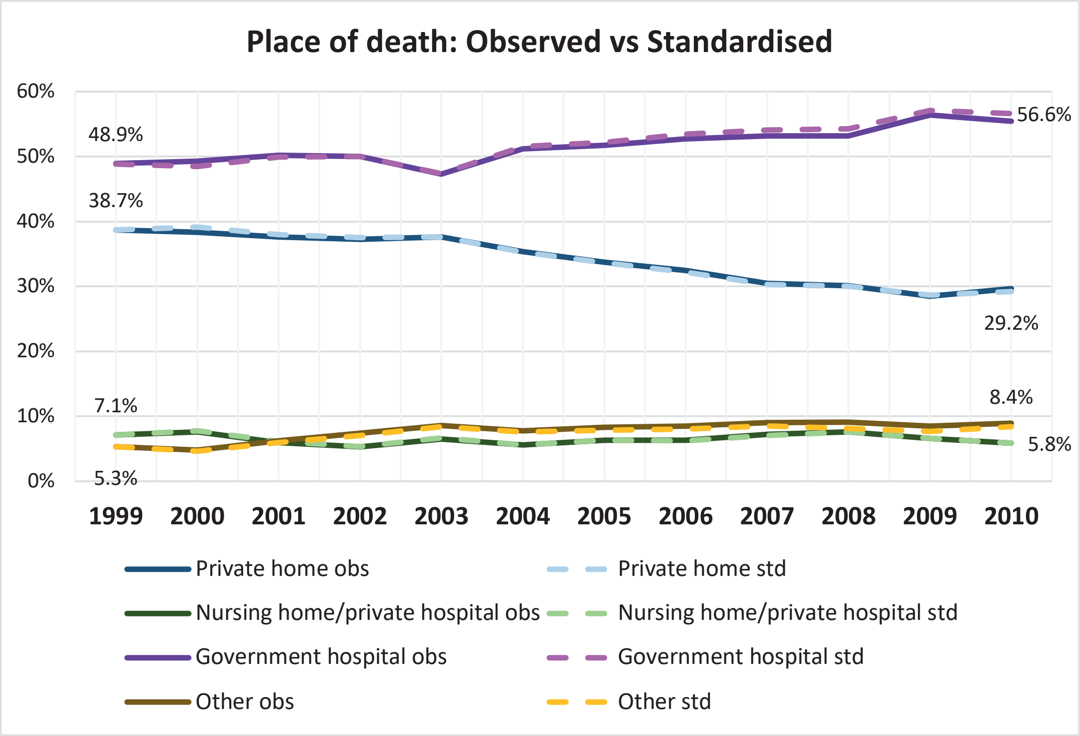
The proportion of male deaths (56.7%) was greater than female and slightly increased over time. Most decedents were aged 60 years and older. The proportion of deaths aged 80 and over increased from 24.0% in 1999 to 26.8% in 2010. The three main recorded causes of death ranked according to frequency were cardiovascular disease, diabetes mellitus and malignancies. The proportion of deaths from cancer increased and deaths from cardiovascular disease decreased over time.

The proportion of all deaths occurring at home decreased from (38.7%) in 1999 to (29.7%) in 2010, deaths occurring in government hospitals increased from (48.9%) to (55.4%) in the same period. The proportion of deaths occurring in a nursing home or private hospital decreased (7.1% to 5.9%), and deaths occurring in other places, inclusive of private geriatric homes, increased (5.3% to 8.9%). When compared, there was little variation in POD between the observed and standardised figures for the period 1999 thru 2010. Deaths at private homes decreased by 9 percentage points (observed) and by 9.5 percentage points (standardised), which are actual decreases of (23.3%) and (24.5%) respectively. Deaths at government hospitals, however, increased by 6.5 percentage points (observed) and by 7.7 percentage points (standardised) with actual respective increases of (13.3%) and (15.7%) (Appendix 1). Figure 1 shows the POD trend for the observed and standardized proportions of decedents over time.

For decedents dying from the subcategory of causes that potentially required PC there was an overall decrease in private home deaths from 1999 to 2010, Figure 2. The largest decrease was in those dying from cancer (51.6% to 31.2%).

Figure 3 shows the observed trend for all government hospital deaths from 1999 to 2010, for decedents dying from the subcategory of ICD10 coded deaths that potentially required PC. Apart for diseases of the nervous system, there was an increase in deaths at government hospitals during the period. The increase was most notable in those dying from cancer (38.4% to 54.7%).

Figure 1. Proportion of all deaths by place of occurrence in Trinidad and Tobago, observed and standardised, 1999-2010. Trend percentages on the figure are standardised values



Abbreviations: obs – observed, std – standardised. Population distributions were standardized using the 1999 population as the standard population for age, sex and cause of death

Figure 2. Proportion of observed home deaths for a subcategory of conditions requiring palliative care in Trinidad and Tobago, 1999-2010

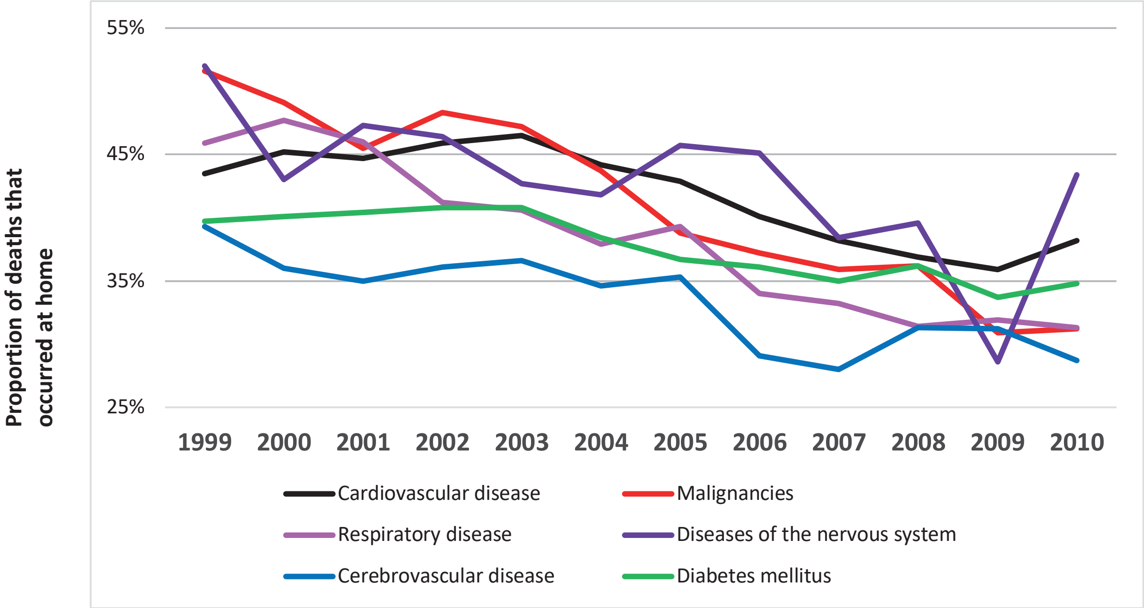
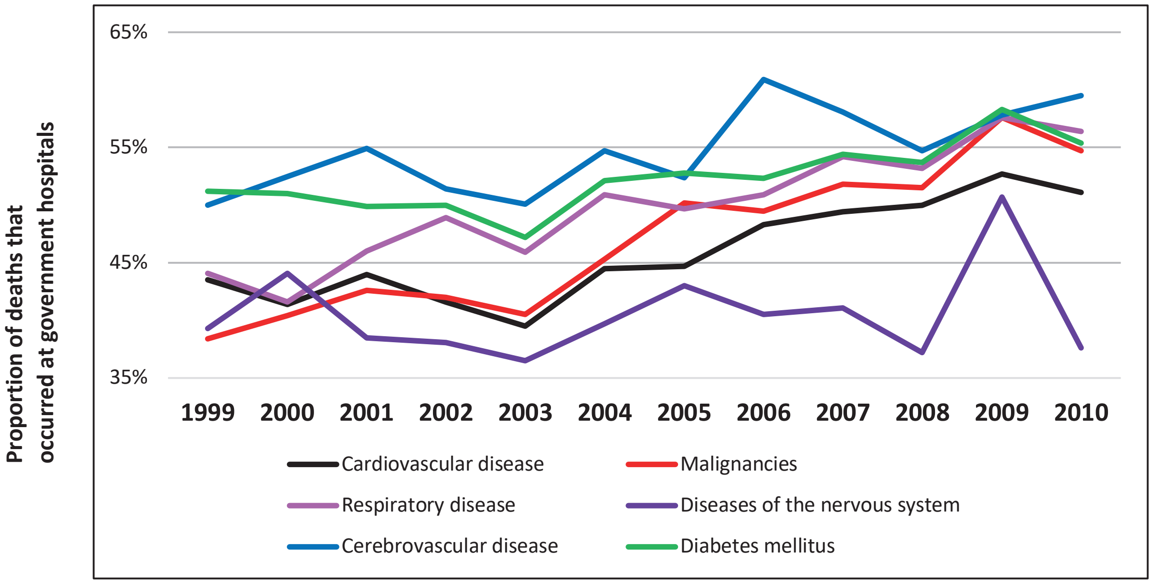


Figure 3. Proportion of observed government hospital deaths for a subcategory of conditions requiring palliative care in Trinidad and Tobago, 1999-2010



DISCUSSION

Summary of the results

In T&T for the period 1999 thru 2010 the proportion of deaths in government hospitals sharply increased while the proportion of deaths in private homes dramatically decreased. Over time, shifts in hospital and home deaths were even more striking for deaths that occurred from conditions in need of PC; most notably in cancer.

Strengths and limitations

This study used available population-level death registry data, a valuable resource for tracking POD spatially and temporally,[20,21] and using robust international research methods improves the possibility for comparison of data and findings to other international studies that used similar methods. This is the first time such information is reported in T&T. However, information on palliative and EOLC in the Caribbean, low-resourced and developing countries is lacking, and trends in POD in relation to palliative and EOLC that consider shifts in underlying cause of death, age and sex of the deceased population have not been studied in the Caribbean including factors such as care services or social resources change that may influence POD. Future research should take these possible factors into account. Other, potential limitations are connected to the information collected on death certificates and the absence of recording other relevant information including; marital status, education level, living arrangement and level of urbanization of the usual place of residence of the deceased. These are factors considered reliable predictors for POD[22] but they are not recorded on the T&T medical certificate of death. This study considered the POD, which may not be the site patients were cared for or spent their last months of life, therefore, the type and quality of care could not be assessed. Additionally, death certificate data are secondary information and the possibility exists that unreliable background information of the deceased including, the certification and coding of some underlying diseases, sociodemographic information and missing values for variables used in this study could alter our findings on the factors that affect POD.[1,22]

Interpretation of the results

Approximately 10,000 deaths occur in T&T each year and the trends in POD likely reflect changes in EOLC practices and in the availability and access to care at the end of life in government hospitals, private homes, nursing and geriatric homes. Data suggests that EOLC and death have become more institutionalised, particularly at government hospitals, and the implications of our findings are considerable.

The growing proportion of deaths at government hospitals appears to be related to a number of factors, e.g., easier access and embedded views and perceptions of the general public around where appropriate environments for EOLC can be provided. Primarily, at the point of service there is no out of pocket cost to access public healthcare. The societal norm could be that dying people seek care at public institutions because government hospitals are seen as a legitimate part of providing general care,[23] but also capable of providing the necessary care, particularly to patients with complex needs,[24] e.g., persons with diseases of the nervous system, and EOLC evolving therefore into a national healthcare policy that has concentrated services at these facilities. This becomes more poignant when we consider the subpopulation likely to need PC, in which there was a considerable increase of hospital deaths over time. Most pronounced was in persons diagnosed with cancer where dying has a predictable trajectory and where EOLC can be planned for accordingly.[25-27] A consequence of the increasing proportion of deaths at institutions like government hospitals, is the need for an proportionate increase in: the number of hospital beds, types and availability of services and adequate palliative and EOLC training of professionals. The trajectory of healthcare cost for EOLC in a hospital setting are significant, studies show that cost of care escalates during the last months of life,[28-30] but hospitals are considered the least desirable place to die in developed Western countries.[3,31] For small low-resourced countries like T&T these circumstances can further burden the provision of EOLC at government hospitals and begs the question whether the observed trend is desirable. Cultural and socioeconomic factors may considerably influence deaths away from a private home, e.g., death and dying are considered taboo, not only in T&T but in the wider English-speaking Caribbean and caring for a dying relative at home may prove too challenging logistically and financially.[32] The changing family dynamic is a likely contributor to an increase of deaths at hospitals, e.g., due to migration it is usual for one or more siblings to reside outside of T&T. Co-ordinating home care of a geographically separated terminally ill family member may not be possible without assistance from extended family and neighbours, who may not be able to cope with the necessary care, and consequently patients are institutionalised. There appears to be a lack of awareness of and need for services to effectively train family members to provide home care.[11] A lack of available support services such as skilled reference persons who are responsible for supporting, coaching and educating caregivers, including volunteers and family members[33] can further impede provision of home care. In the absence of policy like, a do-not-hospitalize option that exists in other countries,[34] or supportive environments that attempts to optimise home deaths[35] by offering out-of-hospital care services like; formal skilled PC home-visits by physicians, nurses or social workers, the trend of declining private home deaths could further increase. There is also a lack of responsive financial support services, where financial compensation can be claimed for palliative home care or an allowance is made for one partner in a two-earner household to take time off from work to care for a relative at home.[36]

In many countries the out-of-hospital trend for EOLC is due partly to an increase of long-term care facilities or nursing homes that offer specialised care for terminally ill patients.[6,23,33,37] A more detailed look is required to get an accurate description of the proportion of deaths that occur at similar facilities in T&T, and the available resources for EOLC in those settings. However, there was an observed increase in deaths in the category ‘other’ that includes geriatric homes, during the period 1999 thru 2010. It could be that an increasing proportion of older persons, either choose to reside or are placed in institutions like geriatric homes and eventually die there, but it is unknown whether residents in these facilities receive any or appropriate EOLC.

The observation of a hospitalization of death trend in T&T is similar to that of some developed countries during the 1990s,[23] and it is likely that similar factors, e.g.; healthcare policy, availability and access to care, played a role in those countries in the past as is the case in T&T. Although a larger proportion of hospital deaths still occurs in many developed countries,[4,6] the difference now is that those countries with developed EOLC priorities have transitioned to out-of-hospital care during the first decade of the twenty-first century.[4,7,33,38,39] A trend usually linked to national, or at least large-scale EOLC programmes or strategies, e.g., involvement of palliative care services,[40] the UK hospice system[41] or the introduction of the hospice benefit scheme in the USA.[42,43] Preference for place of care and place of death have not been studied and are unknown in T&T. This may be an opportunity to explore the need for a national EOLC strategy in T&T that ensures both the increasing number of people dying in government hospitals to receive appropriate EOLC e.g., non-aggressive comfort-oriented care, but that also enables out-of-hospital care options like; hospices, residential aged care, community or home care, if that is the preference of the dying person. Recent moves towards more attention to PC including the establishing of a national PC society and other services may have already initiated a change in the POD and a follow-up study from 2011 onward is warranted. However, additional developments of PC are required to lead to effective improvement. Opportunities to guide this further development in the Caribbean may exist in the recommendations by Spence et al (2018) including: a co-ordinated intra-regional effort to develop PC guidelines, developing a workforce trained in PC, developing models of community-based PC that aims to maximise care of individuals in their own homes and avoid unnecessary hospitalisations, educating patients, and incorporating PC into national health systems.[44]

CONCLUSION

In Trinidad and Tobago between 1999 and 2010 the proportion of deaths in government hospitals increased but private home deaths decreased. A trend that could largely be explained by demographic changes of an aging population coupled with the increasing incidence of chronic degenerative disease and the complex nature for treating terminally ill persons. This may have influenced the concentration of care in government hospitals and the lack of out-of-hospital palliative and EOLC services such as hospice, community or home care. Since POD preference is unknown, these implications can lead to government hospitals becoming the default place to die regardless of their ability to provide the necessary palliative and EOLC, and the undesirable consequences of overburdening, where hospital beds are occupied by terminal patients for extended periods, and thereby increasing healthcare costs. This observation possibly reflects a general trend across the Caribbean and other small developing countries but further studies are warranted. What is needed in T&T is a national strategy on palliative and EOLC that acknowledges both the increasing number of people who seek care at government hospitals and an alternative to accommodate out-of-hospital deaths if this is desired.

What is already known on this subject

- Place of death is an important aspect of quality end-of-life care, it is associated with human dignity and has consequences for healthcare costs.
- Studying trends in place of death provides insight into why changes occur and has relevance in planning of future end-of-life care services, facilities and policies.
- There is scarce empirical data from developing countries on the place of death in relation to palliative and end-of-life care.

What this study adds

- The institutionalisation of death trend in a small developing country is similar to developed western countries and possibly reflects a general trend of other developing countries.
- Government hospitals have had an increased proportion of deaths from cancer.
- Needed is a national strategy on palliative and end-of-life care that acknowledges both the increasing number of people seeking care at government hospitals and an alternative to accommodate out-of-hospital care and deaths.

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PART III GENERATING NEW DATA AND INVESTIGATING THE CIRCUMSTANCES OF END-OF-LIFE CARE AND DYING FROM SERIOUS ILLNESSES USING A MORTALITY FOLLOW-BACK STUDY

5 Developing And Validating A Questionnaire For Mortality Follow-Back Studies On End-Of-Life Care And Decision-Making In Resource-Poor Contexts

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ABSTRACT

Background

Palliative and end-of-life care development is hindered by a lack of information about the circumstances surrounding dying in developing and resource-poor countries. Our aims were to develop and obtain face and content validity for a self-administered questionnaire on end-of-life care provision and medical decision-making for use in population-based surveys.

Methods

Modelled on validated questionnaires from research in developed countries, our questionnaire was adapted to the cultural sensitivity and medico-legal context of Trinidad and Tobago. Two sets of semi-structured face-to-face cognitive interviews were done with a sample of physicians, sampling was purposive. Phase 1 assessed interpretation of the questions, terminology and content of the questionnaire. Phase 2 was tested on a heterogeneous group of physicians to identify and fix problematic questions or recurring issues. Adjustments were made incrementally and re-tested in successive interviews.

Results

Eighteen physicians were interviewed nationwide. Adaptations to questionnaires used in developed countries included: addition of a definition of palliative care, change of sensitive words like expedited to influenced, adjustments to question formulations, follow-up questions and answer options on medications used were added, the sequence, title and layout were changed and instructions for completion were included at the beginning of the questionnaire.

Conclusion

A new instrument for assessing and documenting end-of-life care and circumstances of dying in a small, resource-poor Caribbean country was developed and validated, and can be readily used as a mortality follow-back instrument. Our methods and procedures of development can be applied as a guide for similar studies in other small developing countries.

BACKGROUND

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness” [1]. Substantial progress has been made in the development of palliative and end-of-life care in developed countries, supported by robust population level research including the use of mortality data on the social and clinical circumstances of dying [2]. Such research has led to investment in quality palliative and end-of-life care like choice in the place of care (e.g., private homes, care homes or hospices), quality assurance of end-of-life care in different settings [3,4], and development of appropriate policies and laws addressing ethical issues around withholding or withdrawing care or even medical aid in dying [5].

The majority of people worldwide lacking effective palliative and end-of-life care live in developing and resource-poor countries [6]. These are countries where the capability to provide care for life-threatening illness is limited due to a lack of necessary human and material resources and consequent services, inadequate education and training for healthcare providers, and a lack of governmental policies to support the provision of palliative care [7,8]. But these countries are crippled by the slow development of palliative care, reasons for which can include the lack of a research culture and infrastructure, and appropriate instruments and methods to examine palliative care and the circumstances of dying; attitudes of healthcare providers, the person who is dying and those close to them regarding illness, death and dying; opiophobia, which affects the availability and use of opioids for medical use, and suboptimal symptom management [9].

Apart from recent studies on place of death, there is a complete lack of empirical information on the provision of and access to palliative care in Trinidad and Tobago (T&T), including care characteristics at the end of life [10]. The population is aging [11] and is afflicted by a high prevalence of degenerative diseases [12]. Many of those living with conditions like cardiovascular and cerebrovascular diseases and cancer who could potentially benefit from palliative care are likely not to receive it because palliative care is not a public health priority [13]. Knowledge of the nature of care at the end of life including availability, access and quality, and the circumstances influencing medical end-of-life decisions, can provide better insight into the care and treatment people receive before death. An effective way of obtaining this information is by population-wide monitoring using questionnaires supplemented by mortality data [14]. Questionnaires used for population-based surveys on end-of-life care in developed countries cannot simply be applied to developing or resource-poor countries but require adaptation to the context of the culture, ethico-legal circumstances and available healthcare resources of the target country. All questionnaires traced in the literature were developed for developed countries, confirming the need for reliable, culturally sensitive information on end-of-life care in developing and resource-poor countries. To provide a first scientific epidemiological perspective on end-of-life care conditions, the aims of this study were to adapt and obtain face and content validity for a self-administered questionnaire on end-of-life care provision and medical decision-making for use in population-based mortality follow-back surveys in a small Caribbean country like Trinidad and Tobago.

METHODS

Design

This study concerns the development and cognitive testing of a questionnaire to collect population-based information in a standardised manner on the medical characteristics of palliative care and end-of-life care (that is, care provided in the last 30-days before death), and the circumstances of dying in a developing country. The resource-poor nature of the setting guided our design rationale. We identified mortality follow-back studies as the preferred method to collect epidemiologic and socio-demographic information at the population level as it permits representative sampling of deaths [15]. We used theoretical guidelines for questionnaire design [16] and empirical pre-testing, specifically cognitive interviewing, a strategy to understand how participants interpret information in relation to their medical practice [17]. The COnsolidated criteria for REporting Qualitative research (COREQ) for cognitive interviewing was used [18]. Relevant issues pertaining to terminal illness and dying in T&T were informed by a systematic review of palliative and end-of-life care in the English-speaking Caribbean [9]. Our questionnaire was modelled on a validated questionnaire on end-of-life care and medical decision-making in the Netherlands [19], variations of which were used in the United Kingdom [20], Belgium [21], New Zealand [22], and Canada [23]. Item generation was done by comparing these four questionnaires. Relevant topics were identified and selected for inclusion in our questionnaire but reformulated to the cultural and medico-legal context of T&T. The principal researcher (NJ), a resident and national of T&T with a public health and clinical nursing background, collated a set of context-relevant closed-ended questions into a draft questionnaire. In consultation with co-authors, (KC, LD and JC) the questions were reviewed and adjustments made prior to seeking comments from the Trinidad and Tobago Medical Association (T&TMA) which reviewed for contextual congruence.

Setting and sampling

The study was conducted in T&T from November 2017 to March 2018. Since statistical generalization was not intended, sampling was purposive [24], that is, we deliberately sought participants who were logically assumed to represent the population of physicians with knowledge and experience with end-of-life care. Therefore, a sample of physicians from appropriate medical specialities were recruited by the T&TMA with the inclusion criterion that they provided care to a dying patient within the last year.

Data collection

To validate the questionnaire, semi-structured face-to-face cognitive interviews were undertaken. Draft questionnaires were tested on the sample of physicians to explore and understand their interpretation of the questions and evaluate the kinds of responses generated by participants [25]. Verbal probing [26] was used to further stimulate conversations on issues regarding a word, phrase or concept. An interview guide, (Supplemental 1), was specifically designed to systematise the process, debrief and document participant responses after completion. The interview guide and questionnaire were used as triggers to elicit participant discussion which was divided into two parts. Part I contained general questions, not in the questionnaire, intended to capture the overall understanding, of each participant, of the types of questions being asked, and the structure and logical flow of the questionnaire. Part II contained a series of questions relating to the content of the questionnaire and were asked to understand semantic interpretation by participants and the cultural sensitivity of the questions in the T&T context, e.g., were questions clear, difficult to answer, confronting etcetera. Ethics approval to conduct the study was provided by the Ministry of Health of Trinidad and Tobago. Two sets of interviews were done:

Phase 1

Expert opinion on concepts in the draft questionnaire was sought from specialists experienced in providing palliative care, including general practitioners and hospital-based physicians. Their interpretation of the questions was used to assess terminology and whether the topics were effectively captured. Their comments were integrated into the next iteration of the instrument, which was subsequently reworded and tested with a different group of physicians in phase 2.

Phase 2

The revised draft questionnaire was tested on a heterogeneous subgroup of physicians with characteristics of interest (sex, region of practice and medical specialty) to identify and fix problematic questions or recurring issues [24]. After completing the questionnaire, any additional relevant feedback on semantics, how the questions related to their practice or what was considered meaningful were obtained, changes were made. Each revised version was used in successive interviews.

Interview procedure

Prior to all interviews, participants were e-mailed information about the study and its objective, that is, validating the questionnaire. The interview process and duration were also explained, as was the intention to publish findings in a peer-reviewed scientific article, with deletion of any identifiers such as names of places, individuals or facilities. The principal researcher scheduled appointments with participants at their convenience. Participants were individually interviewed in their offices, clinical settings or other mutually agreed locations. At the interview, participants were asked to read and sign a consent form and give their verbal consent to having interviews audio recorded. They were then prompted to think about the last relevant death they had attended. A highlighter pen was offered to mark items on the questionnaire for discussion with the researcher. Time taken to complete the questionnaire and interview were noted.

Data analysis

Participants were asked to read the questions and relate the scenario to their clinical practice. Information–field notes and audio recordings–from cognitive interviews were systematically documented [24] by the principal researcher. The research team used simple thematic analysis without the use of software to analyse the data. We had group discussions that helped us identify emerging themes, resolve and make systematic decisions on individual problems that arose after interviews. Patterns of problems were grouped, like whether a respondent interpreted a word or question differently than intended, whether an answer option to a question was missing or whether a follow-up question was needed. Incremental adjustments were made after interviews, which were continued until respondents indicated little or no problems with new information, this occurred from the eleventh to eighteenth participant. We made a practical decision that data saturation was reached [27].

RESULTS

A heterogeneous group of 18 physicians was interviewed nationwide (Table 1), medical specialties of the sample of physicians included, general practitioners, oncologists, gerontologists, internal and palliative medicine. The average interview time was 46 minutes (range; 17 to 105 minutes) and the average time to complete the draft questionnaire was eight minutes (range; five to 20 minutes). One participant opted out of the audio recording.

Table 1. Characteristics of participants interviewed

Item	Phase 1 (#)	Phase 2 (#)	Total (#)
Number of interviews	5	13	18
Clinical Specialty			
General practitioners	3	6	9
Specialists	2	7	9
Region			
Trinidad	3	11	14
Tobago	2	2	4
Sex			
Male	2	7	9
Female	3	6	9

General questions

Physicians were asked two broad questions about palliative and end-of-life care to better understand their perceptions of these topics in the cultural context of T&T (Supplemental 2). The first question was ‘what do you think of when I say palliative care?’ Participants responded by mentioning words, phrases or sentences that included goals of care e.g., maintaining comfort or addressing symptom management of terminally ill patients with chronic diseases; improving quality of life by avoiding suffering and assisting the dying through the dying process when a medical cure was not an option; addressing psychosocial issues of the person who was dying and those close to them. The second question was 'what type of care do you consider as palliative care?' Some participants saw no difference between this and the previous question. Others framed it as a dimension of care, e.g., physical, spiritual, or emotional, that can include the family. Others identified it as a physical place of care like a hospice. Responses to the relevance of the question and the structure and flow of the questionnaire are summarised in Table 2. Our intention was to follow the order of general questions in our interview guide, but when asked 'should any of the questions be deleted' and 'were any important questions missing', the order shifted. Participants broadly discussed the meaning of the questions, incorporated their own experiences and remarked on gaps in the healthcare system. This emergent flow was not interrupted but was used as an opportunity to probe participants on these issues.

Specific questions

Participant feedback necessitated changes to the content and structure of the draft questionnaire. The validated questionnaire contains twenty-six questions and is organised into five sections (Appendix 1 for the full questionnaire). The word palliative was removed from the title as some participants were unfamiliar with the term and found it confusing. Several participants had difficulty understanding the terminology of some questions, e.g., some found the filter questions, Q1 (Was this death sudden and totally unexpected?) and Q2 (When was your first contact with the patient?), confusing or irrelevant.

In the section 'Care and treatment,' Q3 asked about prioritising treatment goals in the last seven days of life and which was the main goal. Some participants had difficulty defining a main goal but instead identified the need to treat terminal patients symptomatically, e.g., if a patient had an infection, antibiotics would be given. Other participants did not recognise a difference between care and treatment and the subsequent section on medical practice. Although the World Health Organisation has defined palliative care, a more relatable definition was used because many participants had difficulty with questions in which the term was used. The definition from Palliative Care Australia, “Care that helps people live their life as fully and as comfortably as possible when living with a terminal illness. It identifies and treats symptoms which may be physical, emotional, spiritual or social” [28], was chosen because it succinctly described and was aligned to the dimensions of care physicians encountered during their clinical practice.

Table 2. Selected participant responses to general questions asked during the validation process (November 2017 – March 2018)

Question	Participant Responses
Is there anything in the questionnaire that does not reflect the clinical realties in a Trinidad and Tobago context?	• Questions appear to reflect American culture and laws. • Questions assume that physicians practice some sort of palliative care. • The questionnaire is generic but suitable for the expertise that exists amongst most physicians. • General practitioners who do not regularly provide EOLC may take a longer time to complete the questionnaire. • Some physicians may not be aware of what the terms withholding and withdrawing treatments are in an EOLC situation. • We do not have a referral pathway for palliative care particularly for physicians not working in institutions. • There is no continuity of care and asking questions that relate to patient care, e.g., ‘within the last 30 days’ becomes difficult to trace or track. • The lack of DNR policies corners physicians to continue doing everything to save life, especially in an institutional setting. • A lack of regulations makes it difficult to practice. • Resources like drugs used in EOLC situations are not radially available, e.g., Propofol, morphine and other opioids, and there is a lack of human resources, e.g., counsellors and home care providers. • There are no on-call palliative care physicians, they are all only by referral. • There are not enough inpatient services to match the number of deaths that may require palliative care. • There are no hospices in Tobago. • There is little formal training for the family to care for patients at home.
Are the questions presented in a logical sequence? If not, how could it be improved?	• Some participants thought the sections on ‘care and treatment’ and ‘medical practice’ should be combined.
Does the questionnaire take too long to complete?	• No, there appears to be a lot of questions but it does not take long to complete.
Are the routing directions (e.g., go to question x) clear enough?	• Yes, instructions are helpful.
Is the layout and organisation confusing? If so, how can it be improved?	• The background colour should be changed. • Font size should be increased.

Abbreviations: EOLC – end-of-life care; DNR – do not resuscitate

Under the section ‘Medical practice’ most participants suggested changes were needed to drug categories, e.g., the removal of anaesthetics like Propofol but inclusion of drugs like antiemetics, laxatives, antipsychotics (Chlorpromazine) and benzodiazepines (Diazepam). Most participants also recommended changing the word ‘expedited’ in its relation to the timing of death due to the administration of drugs or withholding or withdrawing of treatment.

The section ‘Decision-making’ required a follow-up question, Q18 (‘why was there no discussion with the patient about the various options related to end-of-life treatments?’) to explain why the patient was not included in the decision-making process.

The final section concerning ‘Information about physicians’ also required a follow-up question regarding competence with communication skills. Q25 (‘do you consider you have enough expertise to communicate adequately with family of patients at the end of life?’). Online supplemental 3 contains a complete list of participant perceptions of questions, comments and changes made to the questionnaire.

DISCUSSION

Summary of results

This study demonstrates that despite challenges in doing public health related research in a resource-poor or developing country context, it is possible to do robust studies by using existing instruments developed for developed countries, but it is important to make relevant cultural adaptations. We developed and validated a self-administered questionnaire, to assess and document palliative and end-of-life care and medical decision-making at the end-of-life. Important changes included: the addition of a palliative care definition and instructions for completion; adjustments to question formulations, wording, sequence of questions and answer options and layout; and removal or addition of questions and answer options.

Strengths and limitations

The questionnaire was validated using face-to-face interviews, which are an effective means of detecting social cues like intonation and body language [29]. To maintain their confidentiality participants were individually interviewed, which enabled unencumbered opinions about issues and questions in the draft questionnaire. Incrementally adjusting the questionnaire when additional relevant feedback was obtained facilitated efficient resolution of important cultural perspectives, problematic words, phrases or issues. By interviewing a heterogeneous mix of physicians whose perspectives represent a range of practices, the questionnaire can be readily used with minimal concern for sensitivity and semantics. Nevertheless, the limited sample typically targeted in cognitively testing questionnaires [26] presents the possibility that some perspectives existing among physicians are not included in this study. Although representativeness for the physician population was not a criterion in this study, but rather variation in their perspectives, it is possible that the physicians interviewed overrepresented those that have some palliative care training or were interested in the topic. Cognitive interviewing is time-consuming for all parties; some interviews were rushed because participants had to return to their clinical duties and information transfer was less effective as a result.

IMPLICATIONS AND INTERPRETATION

Our study is the first of its kind in T&T and makes an important contribution to the field by delivering a validated questionnaire for survey studies on end-of-life practices in a resource-poor country. Further reliability and criterion validity studies, e.g., comparison with actual care provision can further research based on the questionnaire. We extracted relevant questions from validated questionnaires used in developed countries, and adapted them to the cultural, social and clinical context of T&T. Our methods and procedures used to validate the questionnaire can be applied in other resource-poor countries when doing similar studies provided there is sufficient local validation.

In countries that lack data on the circumstances of death and dying, physicians form a critical data source and population-level research requires their participation [30]. As in a similar study [23], physicians clearly understood the need to modify existing questions relating to end-of-life care practices in developed countries, particularly regarding medication availability and use, to reflect clinical practice, including pain and symptom management. In the absence of any supportive national policy on palliative and end-of-life care, semantic meanings of words like ‘expedited’, or ‘withholding and withdrawing’ life-prolonging treatments, when used in relation to the timing of death, were considered confronting.

Physicians interpreted the meaning of such words as an attempt to hasten death. Also evident from interviews was the unfamiliarity of some physicians with the term palliative care, and could be due to a near-total lack of a palliative care culture in medical practice but also to the lack of a substantive palliative care programme at medical schools, the absence of locally available postgraduate training, and the lack of related specialists. This may be detrimental for the quality of medical care delivered to terminally ill patients. To potentially address this issue, physicians can play a key role in advocating for palliative and end-of-life care within their specialty, in lobbying for a palliative care curriculum integrated into existing medical school coursework, and in supporting efforts to improve their palliative care knowledge and skills [31]. When doing health-related research and collecting survey data a number of inherent challenges exist for small developing and resource-poor countries including small populations [32], underdeveloped health infrastructure with a limited range of medical specialists [33], and the lack of a research culture [34]. The latter results in underrepresentation, on the global stage, not only of research from these countries but, importantly, of the epidemiological landscape of their end-of-life care [8].

CONCLUSION

This study supports the need to adapt questionnaires used in studies in developed countries to the culture of a developing country. Modelled on existing questionnaires, a new instrument for assessing and documenting end-of-life care in a small, resource-poor, Caribbean country was developed and validated, and is now ready for use. Use of the questionnaire can further end-of-life care practice in T&T by improving information on the circumstances surrounding deaths. Our methods and procedures for developing the questionnaire can be used as a guide for similar validation efforts in other developing Caribbean countries, or in countries outside the Caribbean where palliative and end-of-life care are at similar stages of development, and can enhance the possibility for cross-national comparability of population-level studies. A useful activity in the validation process would be for research teams to discuss diverging or contradictory comments and perspectives and make well-informed decisions as we did with certain sensitive words.

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6 Palliative And End-Of-Life Care In A Small Caribbean Country: A Mortality Follow-Back Study Of Home Deaths

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ABSTRACT

Context

Empirical information on circumstances of dying from advanced illness in developing countries remain sparse. Evidence indicates that out-of-hospital end-of-life care can have significant benefits like increased satisfaction for the patient and caregivers, and cost-effective for a health care system. Services that are aimed to deliver care at private homes may be a good model for low- and middle-income countries or other low-resourced settings.

Objectives

To examine specialised, generalist and informal palliative care provision, and to describe the end-of-life care goals and treatments received.

Method

A mortality follow-back study with data obtained from general practitioners certifying a random sample of death certificates of adult decedents that occurred between March and August 2018. The questionnaire inquired about the characteristics of care and treatment preceding death.

Results

Three hundred nine questionnaires were mailed, the response rate was 31% (N=96), of which 76% were non-sudden deaths. Of these cases, 27.4% received no palliative care, 60.3% received it from a family member, 39.7% from a general practitioner, and 6.8% from a specialised palliative care service. Comfort maximisation (60.36%) was the main goal of care in the last week of life, and analgesics (53.4%) were the predominant treatment for achieving this goal. In addition, 60.3% received informal palliative care from a family member.

Conclusion

The largest part of end-of-life care at home in Trinidad and Tobago is provided by family members, whereas professional caregivers feature less prominently. To ensure quality end-of-life care, better access to analgesics is needed, and adequate support and education for family members as well as general practitioners are highly recommended.

INTRODUCTION

Empirical information, from low- and middle-income countries (LMIC) including from Latin America and the Caribbean, about the circumstances of dying from terminal illness remain sparse.[1-4] Moreover, in resource-poor settings, a lack of health care policies that support financing for palliative care (PC) including training and educating health care workers, and researchers in the field,[5] and resource deficiencies and infrastructure to generate reliable empirical information makes providing a robust description of palliative and end-of-life care (EOLC) particularly challenging.[6]

Trinidad and Tobago (T&T) is such a resource-poor country where the provision of PC is considered 'Isolated' since it is not integrated into the health care system and a national commitment to PC and practice is lacking.[7] Available service provision, for a population of 1.4 million,[8] includes three in-patient hospices (2 private, 1 government), two community services, an out-patient clinic at a government hospital and a consulting service provided by the government operated hospice. Like other resource-poor countries, T&T is faced with numerous barriers in the provision of palliative and EOLC including: cultural norms precluding open communication about death and dying; unreliable access to opioids and outdated precipitations of its medical use, and underdeveloped education programmes for training formal and informal carers.[3] In the absence of graduate and post-graduate training at local universities, palliative medicine and care are considered developing medical specialities, which limits integration of EOLC into the health care system.

General practitioners (GPs) are, in many countries, vital in providing and co-ordinating palliative and EOLC for their terminally ill patients who prefer to stay at home.[9-11] In countries that have integrated PC into the health care system, GPs manage out-of-hospital care supported by specialised PC providers.[10] However, in resource-poor countries where support by specialised PC services is largely lacking,[12,13] people with PC needs are mostly reliant on their GPs to provide home-based (generalist) care, supported only by informal carers including family members. The most current and complete information (2010) obtained from the national death registry (CSO) indicated that most deaths (55%) occurred at a government hospital and less than 30% at a private home.[14] The choice in place of care and death, and the care decedents received prior to death at different settings are unknown. However, evidence indicates that out-of-hospital EOLC can have significant benefits like increased satisfaction for patients and caregivers, and cost-effective for a health care system.[15,16] Therefore, PC and EOLC services that aim to deliver care at private homes may be a good model for LMIC or other low-resourced settings.

In this context, some important information that can build PC and EOLC health care policies and planning includes an understanding of who is dying at home and why, and what types of PC services, e.g., formal, informal, generalist or specialist, and treatments e.g., aggressive or comfort-oriented are delivered. It is likely that persons dying at home from non-sudden deaths in T&T (and other LMIC) who could benefit from PC are not receiving it at an adequate level. To gain insight into the EOLC trajectories of people who died at home in a resource-poor context, the aims of this study are to; 1) to describe the socio-demographic characteristics of non-sudden deaths occurring in Trinidad and Tobago, 2) to examine decedents' use of specialised, generalist and informal palliative care between non-cancer and cancer deaths, 3) to examine differences in palliative and end-of-life care and treatment between non-cancer and cancer deaths, 4) and to describe the end-of-life care goals and treatments received.

METHOD

Design

We conducted a mortality follow-back study where the sampling framework was obtained from death certificates. The mortality follow-back approach is an efficient means to collect robust population-based information on the last days or months of life.[17] We used and modified the design of a European study protocol,[18] and followed STROBE guidelines for reporting observational or cross-sectional studies.[19]

Setting and population

Our research protocol consisted of two concurrent surveys, a representative sample of deaths that occurred at private homes and a pilot study of deaths that occurred at a main public hospital. Home deaths were sampled at the CSO and questionnaires mailed to the certifying physician. This procedure could not be done for hospital deaths as the timely mailed delivery of questionnaires to physicians, at their respective departments, could not be guaranteed.

However, numerous structural barriers at the hospital setting complicated data collection including: the medical records department being unable to locate patient files, physicians not responding or being able to respond to repeated requests to complete the survey and the high turnover of physicians between departments and from the hospital. It became challenging and impractical to continue this arm of the study and we therefore decided to focus only on home deaths. A random sample of persons aged 18 years or older, of Trinidad and Tobago residents, who died at a private home between March 1 and August 31 2018 was drawn from the death certificates at the CSO. The sampling fraction was 1 in 2. The GP certifying each death in the sample was invited by postal mail to complete a questionnaire about the EOLC and decision making in the specific case.

Survey instrument

A questionnaire was developed, building on the one used in a previous study in the Netherlands,[20] but was adapted by cognitive testing and validation to ascertain it was suitable and relevant to the T&T context, details of which were described in another study.[21] During cognitive interviews for developing the questionnaire we observed that many participants had difficulty with questions in which the term PC was used. Therefore, a relatable definition that described the dimensions of care physicians encountered during their clinical practice was included; "care that helps people live their life as fully and as comfortably as possible when living with a terminal illness. It identifies and treats symptoms which may be physical, emotional, spiritual or social".[22] At the beginning of the questionnaire two filtering questions were asked to identify whether, death of the patient was sudden, that is, totally unexpected due to natural causes (answer options: yes; no), and when was the first contact the physician had with the patient (answer options: at the time of or after death; before death). If the answers were, respectively no and before death, GPs were asked to complete a three-page questionnaire on the care and treatment that had preceded the death involved. Otherwise, GPs were asked to only provide socio-demographic information about themselves. Medical EOLC and treatment practices considered in the questionnaire are shown by some key questions in Table1.

Table 1. Key end-of-life care questions

3. Of the following, which treatment goal was given priority in the last 7 days of life? (*Choose only one answer, i.e. the main treatment goal*)

☐ Cure
☐ Maintenance of function
☐ No overall treatment goals were set
☐ Prolonging life
☐ Maximization of comfort
☐ I have no information regarding the last week of life

4. Which of the following treatment(s) were given in the last 30 days of life? (*multiple answers possible*)

☐ Analgesics
☐ *Artificial hydration
☐ ‡Artificial ventilation
☐ Cardiopulmonary resuscitation
☐ Surgery
☐ I have no information regarding the last 30 days of life
☐ Other, (please specify) . . . .
☐ Antibiotics
☐ †Artificial nutrition
☐ Chemotherapy or other cancer therapy
☐ Dialysis
☐ Transfusion of blood products

6. Which of the following caregivers, besides yourself, were actively involved in the care for the patient in the last 30 days of life? (*multiple answers possible*)

☐ Specialist
☐ Nurse
☐ Psychiatrist/psychologist
☐ Family member
☐ Friend
☐ I don't know
☐ Volunteer
☐ Social worker
☐ Religious/moral counsellor
☐ Religious community member
☐ No one

9. Did this patient receive any §palliative care (at home, in a hospital or elsewhere)? (*multiple answers possible*)

☐ Yes, by a palliative care service
☐ Yes, by a family member
☐ Yes, by a social worker
☐ Yes, by myself and/or other clinician
☐ Yes, by a psychologist
☐ No: go to Question 11

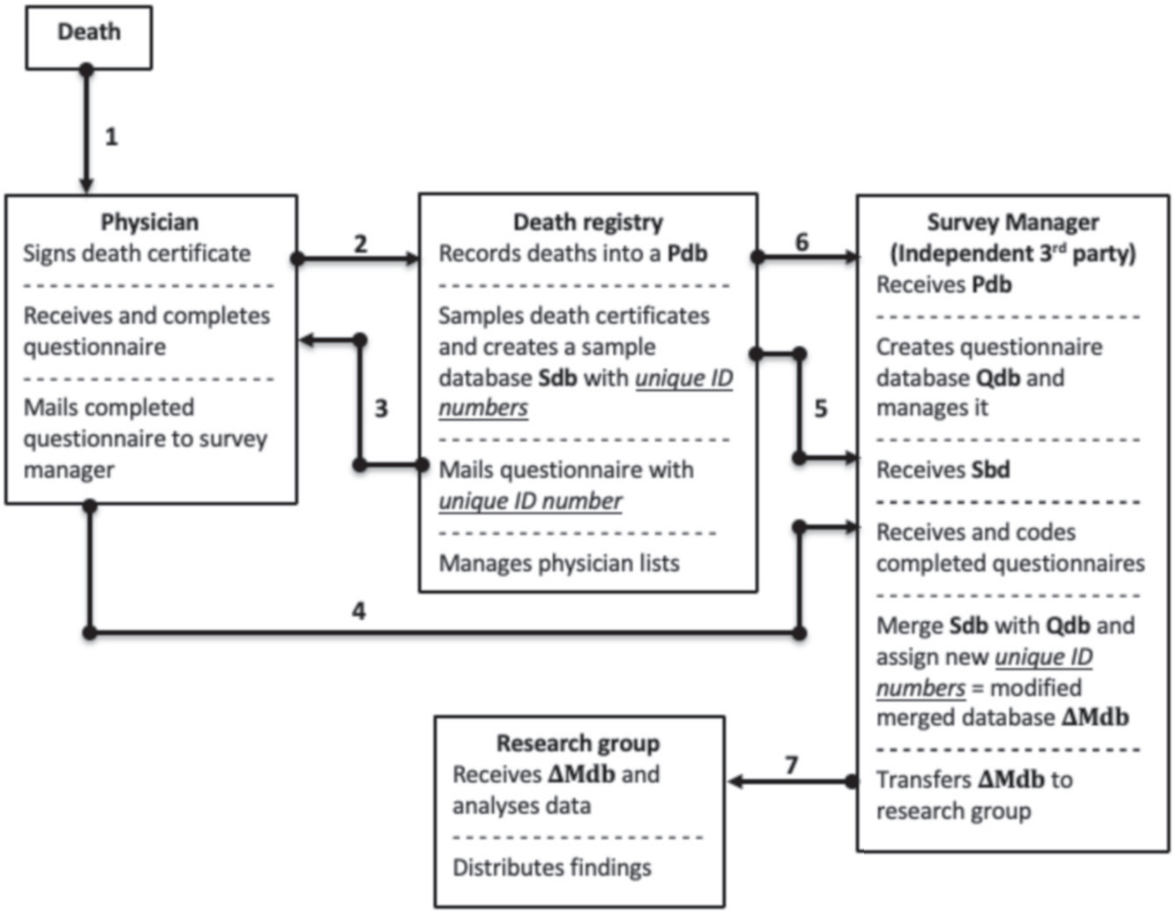
***Artificial hydration includes subcutaneous intravenous line;**
†Artificial nutrition includes parenteral nutrition or percutaneous endoscopic gastrostomy;
‡Artificial ventilation includes intubation or bilevel positive airway pressure.
§By Palliative Care we mean Care that helps people live their life as fully and as comfortably as possible when living with a terminal illness. It identifies and treats symptoms which may be physical, emotional, spiritual or social.[22]

Data collection procedures

Death certificates are paper based and contain demographic information (sex, age, usual place of residence, date and cause of death) of a decedent including the name and professional address of the certifying physician. Physician contact information appearing on death certificates, was manually checked against the most current version (2018) of a national register of medical practitioners. Information is voluntarily provided to the medical board and compiled into a paper bounded register. These certifying physicians were sent the questionnaire by postal-mail. To minimise recall bias a maximum of three months was allowed between death of a patient and the GP being asked to complete the questionnaire; the cut-off was the month not the date of death. An independent third-party, the Trinidad and Tobago Medical Association (T&TMA) was involved in the mailing procedure as intermediary between responding GPs, researchers and the CSO to maintain GP anonymity and guarantee that completed questionnaires could never be linked to a particular patient or GP. Only de-identified patient socio-demographic information was linked to the corresponding completed questionnaires. This procedure included the use of a randomly assigned unique number that was affixed to each mailed questionnaire. As completed questionnaires were received by the third-party a new unique number was affixed and the initial one removed along with any identifiers. By guaranteeing anonymity for GPs the potential risk of social desirability bias and non-response was reduced (Figure 1).

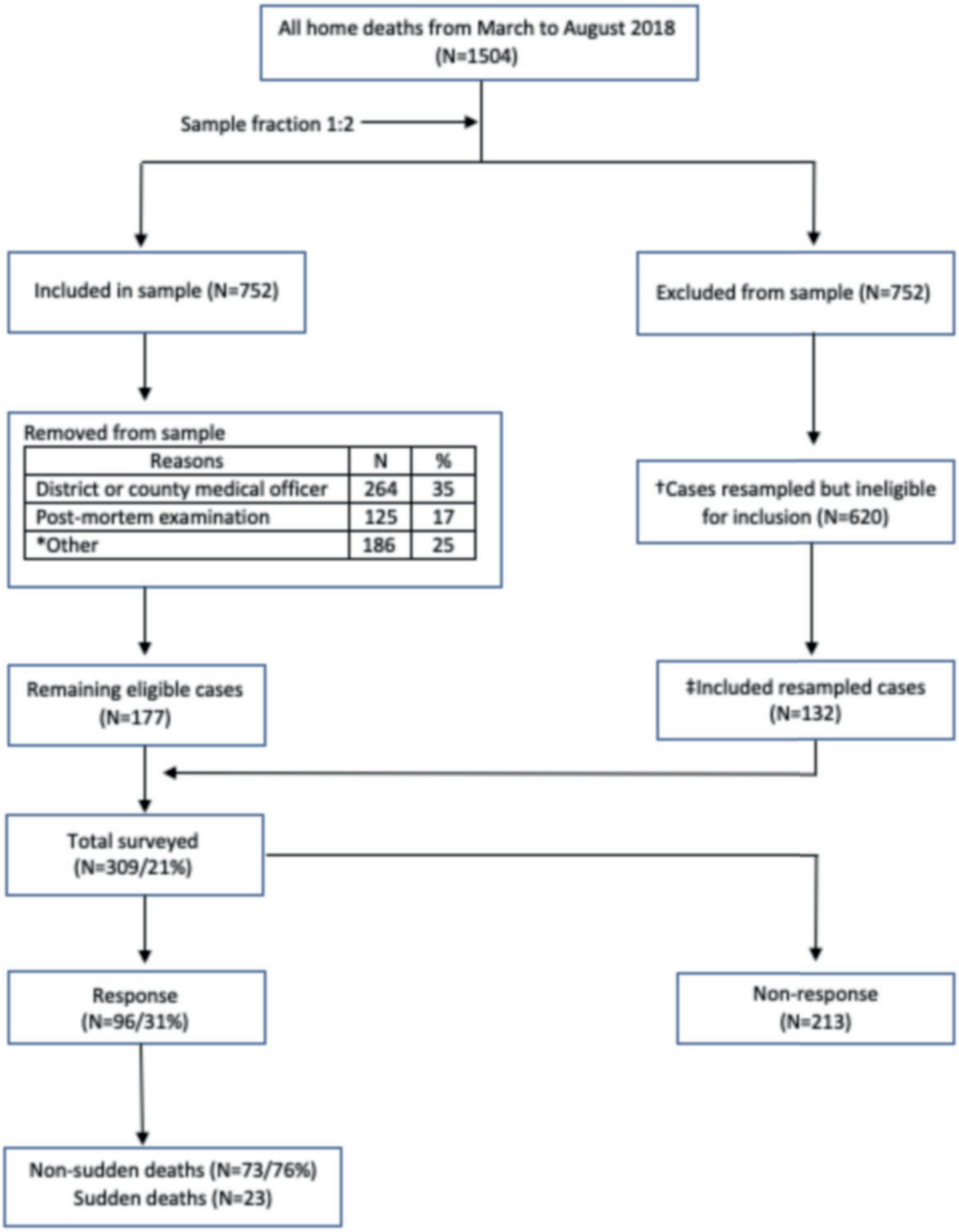
To limit their burden a maximum of three questionnaires were mailed to any one GP, with at most two reminders in cases of non-response. If a fourth case with the same certifying GP was sampled, it was excluded and a new case was resampled from deaths that occurred in the same month of the excluded sample. We noticed during early data collection that a lot of death certificates were completed by district medical officers (DMO) or county medical officers of health (CMOH). These are community based primary care physicians who certify patients often without having access to their medical history or notes. Cause of death, once deemed not suspicious, is often determined from family knowledge of the patient prior to his/her death. The research team felt that these certificates were not indicative of knowledge about decedents in their terminal phase and made the decision to exclude accordingly. This necessitated a change in our research protocol where sampled death certificates completed by DMOs and CMOHs were excluded from the sample. Cases were also excluded when the death was certified by a post-mortem examiner by GPs who retired during the data collection period, or when the GP could not be located at their professional addresses or who explicitly declined to participate in the study. Of the resampled cases, along with aforementioned reasons for exclusion, cases were ineligible when the number of substituted cases within the same month of death were exhausted or the three-month cut-off time between a death and mailing of a questionnaire expired. Our ability to sample cases was impeded by a lag in receipt of death certificates from various district offices to the CSO (Figure 2). A two-month lag in processing death records at the CSO necessitated a delay in data collection (sampling deaths and mailing questionnaires), which began on May 8, 2018 and ended on December 27, 2018. A mail delay in receipt of completed questionnaires to the T&TMA necessitated extending the survey period by one month. The Ministry of Health of Trinidad and Tobago granted ethics approval for the study in January 2018.

Figure 1. Schematic of mailing procedure



Abbreviations: Pbd – population database, Sdb – survey database, ID – identification, Qdb – questionnaire database, ΔMdb – merged database.

Figure 2. Flowchart of sampled death certificates



*Other includes: physician certifying the death case indicated did not want to participate, physician could not be located, illegible writing on death certificate, and saturation of questionnaires per physician.

†Cases ineligible for resampling because: death certificates certified by a district or county medical officer, cases transferred for post-mortem examination, cases were past the three-month cut-off time, and reasons listed as 'Other' above (physician did not want to participate, physician could not be located, illegible writing on death certificate, and saturation of questionnaires per physician).

‡Resampled cases were sequentially selected within the same month of the case that a sample was removed.

Statistical analysis

Questionnaire data (sent and received by postal mail) were recorded and collated in Microsoft Excel spreadsheets. Data cleaning and analysis was done in both SPSS and Excel. Variables of interest: age at death was grouped into the categories (18-49, 50-59, 60-69, 70-79, 80-89 and 90 years or more), sex (male or female), and cause of death grouped into the ICD10 coded categories: cardiovascular diseases (I00–I52, I70–I99), malignancies (C00–C97), liver and kidney diseases (K70, K73, K74; N00–N07, N17–N19, N25–N27), diseases of the nervous system (G00–G99), cerebrovascular diseases (I60–I69), and diabetes mellitus (E08–E13); were described using frequency and cross tabulation analysis. Chi-square tests were used to assess: univariate comparisons for (sex, age, and cause of death) between the total sampled and surveyed populations, bivariate differences between cause of death from cancer versus non-cancer, and representativeness of the total and sampled populations, *p*-values <0.05 were considered significant. These analyses were computed using SPSS 25.

RESULTS

Three hundred nine questionnaires were mailed representing 21% of recorded adult deaths that occurred at a private home and their death certificates available during the study period. 96 questionnaires (31%) were completed of which 73 (76%) were reported as non-sudden deaths. For cases with a response, the proportion of decedents aged 60-years and older was 88.3%, cardiovascular diseases 31.9%, diabetes mellitus 22.3% and malignancies 18.1% were the main recorded causes of death. There were no significant differences for sex ($p = 0.12$), age ($p = 0.62$) or cause of death ($p = 0.85$) between the decedents in the response sample compared to all deaths surveyed (Table 2).

Of the 73 non-sudden deaths 27.4% did not receive any PC, but GPs delivered PC in 39.7% of cases whereas 6.8% received specialised PC. All those who received specialised PC also received care from a GP or family member (data not shown). PC was delivered by a family member in 60.3% of cases. Of these, PC was delivered exclusively by a family member in 22 (30%) cases (data not shown). 17 (29.8%) of non-cancer and 3 (20%) of cancer cases received no PC. However, when PC was delivered to cancer cases, decedents received it mainly from family members 73.3% followed by GPs 60% and specialised PC services 13.3%. Proportionally, cases of cancer received more PC than cases of non-cancer, although differences were not statistically significantly different. Apart from the GP, the caregivers most often involved in care in the last 30-days of life were family members 89.0%, nurses 31.5% and medical specialists 15.1%. These proportions remained consistent regardless of the cause of death, but nurses and medical specialists were less involved in care for non-cancer deaths. There were no statistically significant differences between the caregivers involved in care of decedents dying from non-cancer compared to cancer deaths (Table 3).

Table 2. Socio-demographic characteristics of all home deaths surveyed and for all cases that a response was received

	Cases surveyed		**Cases with response**		
	*N	%	†N	%	P-value
All deaths	309	100	96	100	
Sex					0.12
Male	142	46.3	52	55.3	
Female	165	53.3	42	44.7	
Age					0.62
18 thru 49	10	3.3	5	5.3	
50 thru 59	20	6.5	6	6.4	
60 thru 69	49	16.0	9	9.6	
70 thru 79	74	24.2	22	23.4	
80 thru 89	95	31.0	34	36.2	
90 thru highest	58	19.0	18	19.1	
Cause of death					0.85
Cardiovascular diseases	84	27.4	30	31.9	
Malignancies	69	22.5	17	18.1	
Diabetes mellitus	67	21.8	21	22.3	
Cerebrovascular diseases	27	8.8	6	6.4	
Liver and kidney diseases	21	6.8	9	9.6	
Nervous system diseases	18	5.9	6	6.4	
Other causes of death	21	6.8	5	5.3	
Sudden					‡
Yes	NK	NK	23	24	
No	NK	NK	73	76	

***2 missing cases for sex and cause of death, 3 missing cases for age**
†2 missing cases for sex, age and cause of death
% are valid percentages
P-values <0.05 were considered significant
‡P-values could not be calculated due to empty cells
Abbreviations: NK – Not known

Table 3. Frequency of palliative and end-of-life care provision by different care providers for all non-sudden deaths from non-cancer and cancer causes

	Total (N = 73)		Non-cancer (n = 57) †		Cancer (n = 15) †		
	N	%	n	%	n	%	P-value
***Palliative care received**							
No palliative care	20	27.4	17	29.8	3	20.0	0.54
By family member	44	60.3	32	56.1	11	73.3	0.40
By general practitioner	29	39.7	20	35.1	9	60.0	0.19
By palliative care service	5	6.8	3	5.3	2	13.3	0.38
***Caregivers, other than general practitioner, in last 30-days**							
Family member	65	89.0	52	91.2	12	80.0	0.15
Nurse	23	31.5	16	28.1	7	46.7	0.33
Medical specialist	11	15.1	7	12.3	3	20.0	0.59
Friend	7	9.6	5	8.8	2	13.3	0.68
Religious/moral counsellor	5	6.8	4	7.0	1	6.7	0.76
Religious community member	5	6.8	3	5.3	2	13.3	0.43
Social worker	2	2.7	1	1.8	1	6.7	0.46
Volunteer	1	1.4	0	0	1	6.7	‡
Physician didn't know who was involved in care	1	1.4	1	1.8	0	0	‡
No one	1	1.4	1	1.8	0	0	‡

***Multiple answers possible, hence percentages do not add up to 100%**
†1 missing cause of death
‡P-values could not be calculated due to empty cells

For non-sudden deaths, the most prevalent treatments provided in the last 30-days of life included analgesics 39 (53.4%), antibiotics 25 (34.2%), and artificial hydration 19 (26%), however in 11 (15.1%) of the cases, GPs reported they had no information regarding treatments of their patients during this time. A greater proportion of deaths from cancer received analgesics 93.3% than non-cancer 43.9% deaths, which was statistically significant (p = 0.003). The reported goals of care in the last seven days of life focused mostly on maximising comfort of patients 44 (60.3%) rather than maintenance of function, prolonging life or seeking a cure. Comfort maximisation was proportionally greater for cases of cancer 80% than non-cancer 54.4%, maintenance of function 14%, prolonging life 8.8% or cure 3.5% were also being pursued. There were no statistically significant differences between goals of care of decedents dying from non-cancer compared to cancer deaths (Table 4).

Table 4. End of life treatments of non-sudden deaths in the last 30-days of life and goals of care in the last 7-days of life among non-cancer and cancer cases

	Total (N = 73)		Non-cancer (n = 57) †		Cancer (n = 15) †		
	N	%	n	%	n	%	P-value
***Treatments in last 30 days**							
Analgesics	39	53.4	25	43.9	14	93.3	0.003
Antibiotics	25	34.2	20	35.1	4	26.7	0.70
Artificial hydration (intravenous line, subcutaneous)	19	26.0	15	26.3	4	26.7	0.88
Artificial nutrition (parenteral nutrition, P.E.G. tube)	6	8.2	5	8.8	1	6.7	0.84
Dialysis	2	2.7	2	3.5	0	0	‡
Chemotherapy or other cancer therapy	2	2.7	1	1.8	0	0	‡
Artificial ventilation (intubation or BPAP)	1	1.4	0	0	1	6.7	‡
Cardiopulmonary resuscitation	1	1.4	0	0	1	6.7	‡
Surgery	1	1.4	1	1.8	0	0	‡
Other treatment	15	20.5	15	26.3	0	0	‡
Physician had no information regarding the last 30-days of life	11	15.1	10	17.5	1	6.7	0.30
§Main Goals of Care in last 7 days							0.38
Comfort maximation	44	60.3	31	54.4	12	80.0	
Maintenance of function	8	11.0	8	14.0	0	0	
Prolonging life	6	8.2	5	8.8	1	6.7	
Cure	2	2.7	2	3.5	0	0	
Physician had no information regarding the last week of life	13	17.8	11	19.3	2	13.3	

***Multiple answers possible, hence percentages do not add up to 100%**
†1 missing cause of death
‡P-values could not be calculated due to empty cells
§ Physicians were asked to choose *only* one main goal
Abbreviations: PEG – percutaneous endoscopic gastrostomy; BPAP – bilevel positive airway pressure

DISCUSSION

Summary of main findings

In caring for terminally ill patients who died at private homes in Trinidad and Tobago, most GPs reported that comfort maximisation (60.3%) was the main goal of care in the last week of life, and analgesics (53.4%) were the predominant treatment for achieving this goal in the last 30-days of life. Despite scientific evidence of the advantages of palliative care,[23-26] 27.4% of decedents, dying non-suddenly from conditions indicative of PC did not receive it. Family members (60.3%) and GPs (39.7%) play important roles as they are the most involved caregivers for their dying relatives and patients regardless of the disease and they provide a large part of the PC.

Strengths and limitations

A questionnaire was specifically developed and validated for this study and this paper presents the first national data on EOLC and medical treatments reported by GPs in any English-speaking Caribbean country. We used a high sampling frame, (1:2), and similar robust research methods of studies done in developed countries with advanced palliative and EOLC systems,[27-29] and there is opportunity for comparison of findings.

The mortality follow-back approach is an efficient means to collect national information and can describe the last days and months of life—a time when interviewing dying persons is sensitive, potentially inappropriate and logistically challenging.[17] Study limitations include the inherent shortcomings of postal surveys like social desirability bias, recall and response bias[30,31] and our study cannot exclude such limitations. Compared to similar studies[27-29] our response rate is low 31% and we cannot generalise about the entire population of non-sudden deaths. Some possible reasons for the response rate include the efficiency of the postal service, unfamiliarity of GPs with this type of survey and mailing procedure, or voluntary participation in postal surveys is not a cultural norm in T&T.

We cannot exclude the possibility that the sensitive nature of questions and lack of supportive national policy and legislation for medical practitioners regarding EOLC limited physician participation or truthfulness about their own end-of-life practices.[32] Bias of GPs with an interest in the field of palliative medicine and EOLC could have affected the responses. Our sample only contained cases where a GP certified the death as all non-sudden deaths certified by DMOs, CMOHs etcetera were excluded. While the eventually obtained sample does not differ significantly in cause of death and sociodemographic characteristics from all home deaths in the corresponding period, it is possible that our obtained sample may be biased toward people who died with a clearer and more predictable EOLC trajectory.

The lag between a death and the physician receiving a questionnaire was reasonably short at 3-months. A shorter delay could probably reduce possible recall bias but was not possible due to the time between death, medical certification and the receiving of the certificates at CSO. Additionally, information on some death certificates was incomplete, e.g., decedent age or sex were missing, or name of the certifying GP or their contact details were illegible, which created a systemic barrier of obtaining accurate decedent demographics or of identifying and contacting the GP.

INTERPRETATION OF THE RESULTS

Our data shows variation in the type of PC used with little specialist involvement in EOLC. Not all terminal patients will require specialised PC,[33,34] but this pattern of use could relate to the few number of specialised PC services or the lack and insufficient coverage of available services in T&T. GPs play a central role in primary care as they are often patients' first contact for medical care and act as referral gatekeepers to specialised services,[34] but GPs may be unfamiliar with the types of specialised PC services available and how to refer their patients. Although more GPs were involved in PC than specialised PC services, 40% of cases, compared to developed countries, (65% in England 2003-04, 70% in Australia 2007, 76% in Belgium 2005, 89% in Denmark 2006)[35-38] this level is quite low. Low GP involvement could reflect the systemic lack of support, in the health care system, for GPs to care for patients at the end of life. Another likely reason may include the absence of palliative medicine and care curriculum at medical schools and the consequent uncomfortable feeling of some GPs perceived inability to manage end of life scenarios, for example, late identification of and inadequate symptom management.[39] Nevertheless, given the relatively few available PC services and professional carers, it appears that GPs are often the sole formal PC providers of terminally ill patients and could contribute to suboptimal patient care.

A large proportion of decedents received informal PC that was mainly delivered by family members. In Caribbean and other LMIC there is a cultural tradition of family members caring for or being involved in the care of their terminally ill relatives either at home or in hospital.[3,40-42] Informal caregivers play a vital role in supporting people with terminal illnesses.[43-45] However, in resource-poor countries that lack social security systems and formal PC support, we cannot ignore the possibility that there were no alternatives, besides family, to provide palliative and EOLC. Our data showed that family members exclusively delivered PC in 30% of cases. In this instance, the issue about receiving PC and the type of care becomes less about tradition and more about making do.[46] In addition, the knowledge, capacity and practical skills of family members to deliver PC at home to their relatives is unknown but likely to be small because PC is not a health care system priority and resources for educating family caregivers in these skills is lacking. In a resource-poor EOLC environment, it may be unsurprising that 27.4% of cases dying non-suddenly received no PC.

Although non-malignant diseases were more than twice as common as cancer it appears that patients with cancer received more attention. Proportionally they received more PC, more care in the last 30-days of life from nurses and medical specialists and were more likely to receive analgesics. Traditionally, PC programmes concentrated on the needs of cancer patients[47,48] as malignancies have a predictable trajectory allowing for time to prepare EOLC needs, but there is equal need for PC in patients with non-malignant diseases.[49-51] It is possible that GPs were more sympathetic to patients with cancer and willing to treat cancer related pain more aggressively than other types of pain. A factor that could contribute to suboptimal PC of some non-cancer patients in the community.[52,53]

An essential but complex phenomenon of EOLC is prognosticating and deciding on an appropriate care trajectory. As death becomes imminent, comfort maximisation assumes priority over other care goals.[54] GPs indeed reported that comfort care was the primary goal in the last seven days prior to death, and more than half of the treatments provided to patients within this time were analgesics. However, in approximately 40% of non-sudden home deaths maximising comfort was not the primary goal of care, instead it was prolonging life, maintaining function or even seeking a cure. This suggests that symptom management was possibly not a priority or GPs were reluctant to switch to PC given a lack of knowledge and experience. Medical practitioners in the Caribbean are reluctant to use opioid analgesics regardless of the end-of-life trajectory of the patient because of, stigma, misplaced fear of adverse drug side effects or causing addiction,[3,4,55] or simply because a reliable and consistent supply of effective analgesics are not available.[56]

Recommendations

This study suggests that serious challenges exist in the availability, access to, and delivery of palliative and EOLC in T&T. There is opportunity here for stakeholders to strengthen functioning of the health care system and facilitate access to PC and pain relief by following some broad recommendations described in a recent Lancet Commission report[48] including implementing public education programmes and awareness-building campaigns around PC that focus on community care, incorporating PC and pain relief into the national health agenda and support this with appropriate financing, establish effective legal and regulatory guidelines for the safe management of opioid analgesics and other controlled medicines, and promote effective policy making by encouraging better evidence from robust research that includes PC in government-funded research programmes.

However, what is urgently needed is support and education for informal carers like family members and PC training for GPs. Family caregivers appear to be the backbone in delivering PC to their terminally ill relatives, and they do so possibly without any financial, social and psychological assistance from government. It is imperative that family caregivers receive basic psychoeducational support or training to increase their capacity to provide support and care for their dying if the need arises.[57] GPs need to deliver high-quality, safe, timely and patient-centred PC[58] and should receive structured training in PC including communication skills and bereavement care.[59] Multifaceted postgraduate strategies for improving GP PC training could include didactic learning, seminars, virtual classrooms via the internet and mentorship by specialists.[60] There is also opportunity for family members and GPs to co-ordinate and increase their capacity by working together as an integrated community service, promoting a responsive and cost-effective delivery of care in the community.[61,62] An integrated community-based delivery system of PC is a sustainable model and has potential in resource-poor settings and LMIC.[62]

CONCLUSION

Professional PC and EOLC is mostly delivered by GPs but there appears to be inappropriate EOLC in the last seven-days of life like seeking cure or prolonging life, and low use of analgesics during this time were reported. Our study indicates the prominence of family members in delivering PC at home to their terminally ill relatives, but the quality of care is unknown and programmes to train family members in providing EOLC seem warranted.

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KEY MESSAGE

Our study shows that informal caregivers, particularly family members, are most important in delivering palliative care to their terminally ill relatives in the community. Programmes to train family members to provide necessary end-of-life care are critically important particularly for resource-poor countries that lack trained professionals.

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7 Medical End-Of-Life Decision-Making In A Small Resource-Poor Caribbean Country: A Mortality Follow-Back Study Of Home Deaths

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Submitted

ABSTRACT

Background

In resource-poor countries, including in Latin American and the Caribbean, empirical information about the characteristics and incidence of medical end-of-life decisions–withholding or withdrawing potentially life-prolonging medical treatments–is largely absent.

Aim

To describe the incidence and decision-making characteristics of medical end-of-life decisions taken prior to the death of people who died at home in Trinidad and Tobago.

Design

Mortality follow-back study.

Setting/participants

A representative sample of deaths occurring at home in 2018 was drawn from death certificates at the national death registry. The general practitioners who certified the deaths were sent a questionnaire.

Results

The sample consisted of 309 adult deaths. Response rate 31% (N=96), physicians were: mostly male (79.2%), practiced medicine for more than twenty-years (63.5%), had no formal palliative care training (69.8%). Non-sudden deaths represent 76% (N=73), of these, medications to alleviate pain and symptoms in the last 7-days of life were administered in 65.8%, including opioids 21%. Potentially life-prolonging treatments were withheld in 9.6% but none withdrawn. No physician/patient discussions about various end-of-life treatment options occurred in 61.6%. Compared to physicians with no formal training in palliative care, those with training more often: prescribed or administered opioids in the last 7-days of life (35.7% vs 11.1%, *p=0.01*), had discussions with patients about end-of-life treatment options (60.7% vs 24.4%, *p*=0.002), and discussed medication use to alleviate pain and other symptoms with patients (50% vs 17.8% (*p*=0.004).

Conclusion

General practitioners trained in palliative care discussed and shared end-of-life decision-making with their patients. The necessary regulatory support to further develop palliative care in Trinidad and Tobago in needed.

BACKGROUND

Advances in modern medicine can prolong life including the life of persons with degenerative or incurable illnesses. Medical end-of-life decisions (MELDs) are a hotly debated topic because prolonging life of terminally ill patients may not be the most appropriate or desired goal of, but rather the quality of their life in the final days or weeks.[1-4] MELDs can include: non-treatment decisions such as withholding or withdrawing potentially life-prolonging treatments no longer considered beneficial, intensification of medications administered to alleviate pain or other symptoms that may have unintended side-effect (rendering a patient unconscious or influence the timing of death), and physician-assisted suicide or euthanasia in countries or territories where this is legal.[3-5]

Several factors are identified with influencing MELDs including attitudes and preferences of patients, their families and healthcare providers towards death and dying, and patient characteristics like age, gender, level of education and socio-economic status.[6] Communication about end-of-life care and MELDs can be difficult for physicians, patients, and their families as decisions are often perceived as 'life or death'.[7] Increasing evidence suggests that appropriate care with low medical intensity near death is associated with more discussions between patients and their physicians about goals and expectations for medical end-of-life care.[8,9] In fact, communication and shared decision-making involving patients' input in planning their treatment promotes their satisfaction and compliance with care, improves relationships between healthcare providers and patients and is increasingly recognised as a quality indicator for care.[10]

The need for good end-of-life care may be greatest in resource-poor countries, including Latin American and the Caribbean,[11,12] yet many who need it do not benefit because services are either limited or non-existent.[11,13] Resource-poor relates to the limited capability to provide appropriate care for life-threatening illness due to a lack of necessary human and material resources, inadequate education and training for healthcare providers, and a lack of governmental policies supporting the provision of palliative care, [12,14] including access to opioids for medical use.[11] A good example is Trinidad and Tobago (T&T), a small Caribbean country where palliative care provision is considered 'Isolated', that is, lacking a national commitment to palliative care and practice,[12] absence of palliative medicine curricular at local universities, and data and infrastructure to generate reliable empirical information about the circumstances of dying from terminal illness is lacking.[14,15]

In countries with developed palliative care services general practitioners (GPs) manage out-of-hospital care supported by specialised palliative care providers,[16] who are instrumental in providing and co-ordinating palliative and end-of-life care for their patients preferring to stay at home.[16-18] The use of specialist palliative care in home settings may be beneficial to patients and caregivers,[19] but in resource-poor countries specialist services and support is lacking and people rely mostly on their GPs to provide home-based (generalist) care, supported by informal carers including family members. Research showed that GPs were the predominant provider of formal palliative care to persons dying at private homes from terminal illnesses in T&T.[20]

In this study, we focus on MELDs taken prior to death in T&T, and will address the following research questions: 1) What is the incidence of different types of MELDs made for persons dying at home? 2) What are the characteristics of the decision-making process at the end of life? 3) Does end-of-life decision-making differ depending on the physicians' formal palliative care training?

METHOD

Design

We conducted a population-based mortality follow-back study based on death certificates, where GPs had certified a sample of deaths occurring at home. This design is viewed as an efficient means to collect robust population-based information on the last days or months of life.[24] A modified design of a European study protocol[25] was used. We followed STROBE guidelines for reporting observational or cross-sectional studies.

Setting and participants

A random sample of persons aged 18 years or older, of Trinidad and Tobago residents, who died at a private home between March 1 and August 31 2018 was drawn from death certificates at the national death registry, the Central Statistical Office (CSO). All deaths in Trinidad and Tobago are certified by a physician and sent to the CSO for mortality statistics purposes. The sampling fraction was 1 in 2. The GP certifying each death in the sample was invited by postal mail to complete a questionnaire about the care and decision-making in the specific case. Multiple deaths could have been certified by the same GP in our survey.

Our intended study included sampling home and hospital deaths. To test the feasibility of doing such a study at a hospital a pilot study of deaths at a main government-hospital was attempted. However, we encountered numerous structural barriers at the hospital that impeded data collection including: time physicians had allotted to complete the questionnaire were delayed or interrupted because patient files were unavailable upon their request, and a high turnover of physicians between departments and from the hospital complicated the process of physicians receiving and completing a questionnaire. It became impractical to continue this arm of the study and we therefore decided to focus only on home deaths.

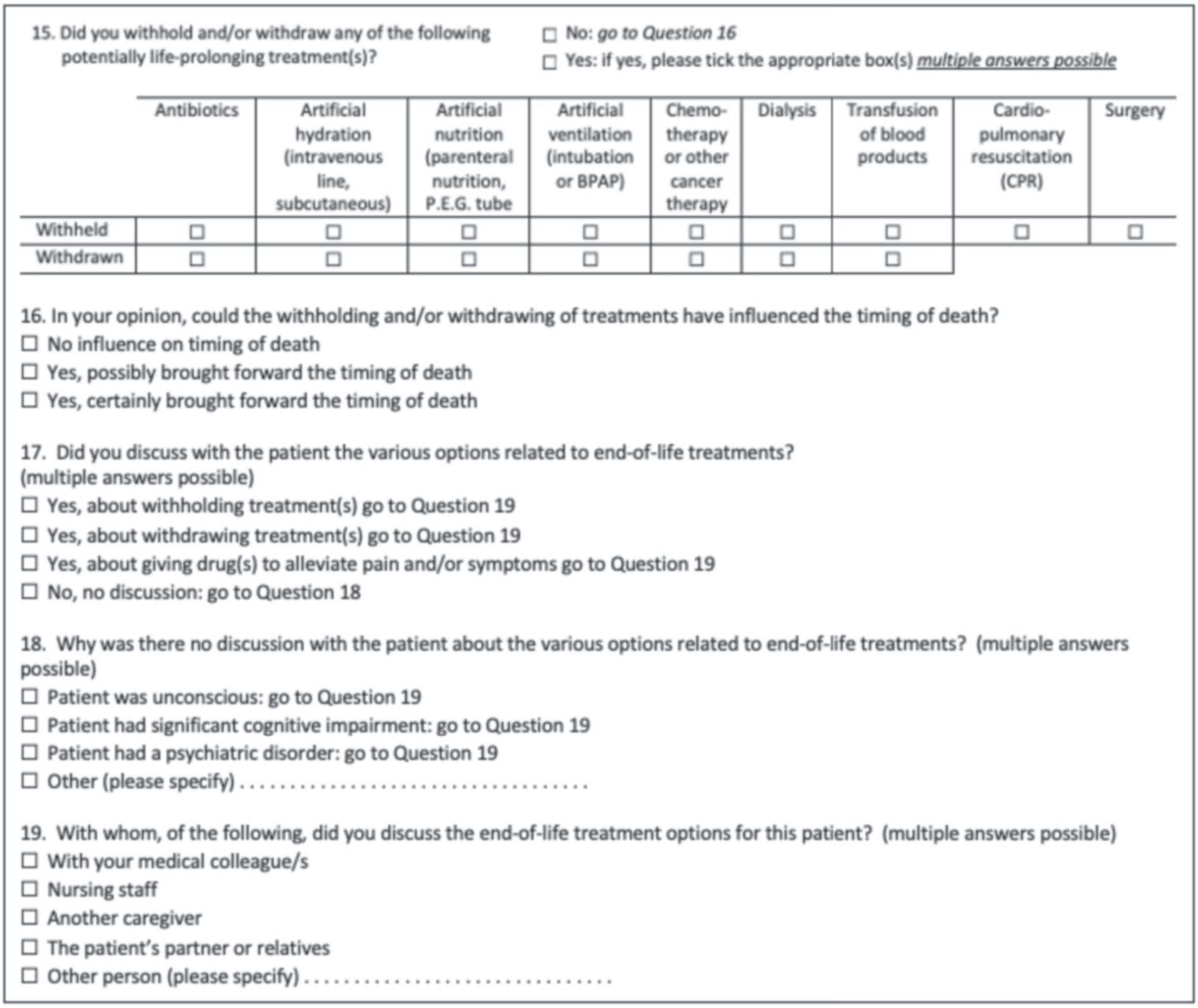
Survey instrument

A questionnaire was developed building on a study in the Netherlands.[4] It was adapted by cognitive testing and validation to ascertain it was suitable and relevant to the T&T context, details were described (including a version of the final questionnaire) in a previous study.[26] At the beginning of the questionnaire two filtering questions were asked, ‘was the patient death sudden’, that is, totally unexpected due to natural causes and end-of-life care could not be ascertained (answer options: yes; no), and ‘when was the first contact the physician had with the patient’ (answer options: at the time of or after death; before death). If answers were, respectively no and before death, GPs were asked to complete a three-page questionnaire on the care and treatment that preceded the death involved. Otherwise, GPs were asked to only provide sociodemographic information about themselves. Some key MELD questions considered in the questionnaire are shown in Box 1.

Data collection procedures

Death certificates are paper based and contain sociodemographic information (sex, age, usual place of residence, date and cause of death) of a decedent including the name and professional address of the certifying physician. To minimise recall bias a maximum of three months was allowed between death of a patient and the GP being asked to complete the questionnaire. An independent third-party, the Trinidad and Tobago Medical Association (T&TMA) was involved in the mailing procedure as intermediary between responding GPs, researchers and the CSO to maintain GP anonymity and guarantee that completed questionnaires could never be linked to a particular patient or GP.

Box 1. Key medical end of life decision-making questions



15. Did you withhold and/or withdraw any of the following potentially life-prolonging treatment(s)?

☐ No: *go to Question 16*
☐ Yes: if yes, please tick the appropriate box(s) *multiple answers possible*

	Antibiotics	Artificial hydration (intravenous line, subcutaneous)	Artificial nutrition (parenteral nutrition, P.E.G. tube	Artificial ventilation (intubation or BPAP)	Chemo-therapy or other cancer therapy	Dialysis	Transfusion of blood products	Cardio-pulmonary resuscitation (CPR)	Surgery
Withheld	☐	☐	☐	☐	☐	☐	☐	☐	☐
Withdrawn	☐	☐	☐	☐	☐	☐	☐		

16. In your opinion, could the withholding and/or withdrawing of treatments have influenced the timing of death?
☐ No influence on timing of death
☐ Yes, possibly brought forward the timing of death
☐ Yes, certainly brought forward the timing of death

17. Did you discuss with the patient the various options related to end-of-life treatments? (multiple answers possible)
☐ Yes, about withholding treatment(s) go to Question 19
☐ Yes, about withdrawing treatment(s) go to Question 19
☐ Yes, about giving drug(s) to alleviate pain and/or symptoms go to Question 19
☐ No, no discussion: go to Question 18

18. Why was there no discussion with the patient about the various options related to end-of-life treatments? (multiple answers possible)
☐ Patient was unconscious: go to Question 19
☐ Patient had significant cognitive impairment: go to Question 19
☐ Patient had a psychiatric disorder: go to Question 19
☐ Other (please specify) . . . .

19. With whom, of the following, did you discuss the end-of-life treatment options for this patient? (multiple answers possible)
☐ With your medical colleague/s
☐ Nursing staff
☐ Another caregiver
☐ The patient's partner or relatives
☐ Other person (please specify) . . . .

Only de-identified patient sociodemographic information was linked to the corresponding completed questionnaires (Appendix 1). A maximum of three questionnaires with at most two reminders were mailed to any one GP. If a fourth case with the same certifying GP was sampled, it was excluded and a new case resampled from deaths that occurred in the same month of the excluded sample. Excluded from the sample were death certificates completed by district or county medical officers of health who are community based primary care physicians that certify deaths without having access to the decedent medical history or notes. Cases were also excluded when the death was certified by a post-mortem examiner, by GPs who retired during the data collection period, or when the GP could not be located at their professional address or who explicitly declined to participate in the study. Additionally, resampled cases were excluded when the number of substituted cases within the same month of death were exhausted or the three-month cut-off time between a death and mailing of a questionnaire expired.

A lag in receipt of death certificates from various district offices to the CSO impeded our ability to sample cases, and a two-month lag in the CSO processing death records necessitated a delay in data collection (that is, sampling deaths and mailing questionnaires), which began on May 8, and ended on December 27, 2018. Disruptions in the mail service also necessitated a one-month extension of the survey period. Questionnaire data (sent and received by postal mail) were recorded and collated in Microsoft Excel spreadsheets and linked to the death certificate information by the T&TMA. The Ministry of Health of Trinidad and Tobago granted ethics approval for the study in January 2018.

Statistical analysis

Data cleaning and analysis was done in both SPSS and Excel. Sociodemographic information of attending general practitioners responding to the survey were grouped into the following categories: sex (female, male) and years of practice (less than 5 years, 5–10 years, 11–15 years, 16–20 years, more than 20 years). Their formal palliative care training was dichotomised; ‘no’ and ‘other’ were condensed into (no) and ‘yes, as part of my medical degree’ and ‘yes, postgraduate training’ into (yes). Associations were described using frequency and cross tabulation analysis. Chi-square tests were used to assess bivariate differences between end-of-life decision-making by GPs in relation to their formal training in palliative care, *p*-values <0.05 were considered significant. These analyses were computed using SPSS 25.

RESULTS

The sample consisted of 309 deaths representing 21% of recorded adult deaths that occurred at a private home and their death certificates available during the study period. 96 questionnaires (31%) were returned completed (Appendix 2). There was no significant difference in cause of death and sociodemographic characteristics between the obtained sample and all home deaths in the corresponding period (Appendix 3). The attending GPs of the included cases were mostly male (79.2%), practiced medicine for more than twenty-years (63.5%), and had not received any formal palliative care training (69.8%). Most considered that their communication expertise with patients 78.1% and patients' family members 84.4% was gained through experience and informal training (Table 1). Additionally, 75.5% of physicians feel unsupported by current national protocols concerning the preferred medical management of their terminally ill patients.

Seventy-three (76%) deaths were reported as non-sudden, hence, a MELD by the GP was theoretically possible in these cases. In 34.2% of these no medications were used to alleviate patient symptoms in the last seven-days of life (Table 2). But when given, the most common were Morphine or other opioids 20.5% and Diazepam or other benzodiazepines 17.8%. In over 82% of the cases when medications were administrated in the last seven-days of life, they had no influence on the timing of death, or possibly delayed the timing of death. Of the non-treatment decisions, no treatments were withdrawn but life-prolonging treatments were withheld in 7 (9.6%) deaths. The most common withheld treatments were artificial hydration and artificial nutrition 6.8% followed by artificial ventilation and cardio-pulmonary resuscitation 4.1%.

There were no discussions between GPs and patients about decision-making on various end-of-life treatment options in 45 (61.6%) deaths, but when discussions occurred, the most common were about giving medications to alleviate pain and/symptoms 22 (30.1%), withholding treatments 10 (13.7%) or withdrawing treatments 3 (4.1%) (Table 3). Apart from the GP, other caregivers involved in discussions were, the partner or relatives of the patient 55 (75.3%) or medical colleagues 8 (11%). Some patients 8.2% did express a wish for the end of life to be hastened, but only 2.7% did so explicitly to their GP.

Table 1. Characteristics of All general practitioners who responded to a questionnaire

	Total (N = 96)	
	*N	%
Sex:		
Female	20	20.8
Male	76	79.2
Years of practice:		
Less than 5 years	1	1.0
5 – 10 years	10	10.4
11 – 15 years	8	8.3
16 – 20 years	16	16.7
More than 20 years	61	63.5
†Formal training in palliative care:		
‡No	**67**	**69.8**
Yes	**44**	**45.8**
As part of my medical degree	(22)	(22.9)
Post graduate degree	(22)	(22.9)
†Expertise in communicating with patients at the end of life:		
No	**15**	**15.6**
Yes	**86**	**89.6**
Through experience/informal training	(75)	(78.1)
Through formal training	(11)	(11.5)
†Expertise in communicating with family of patients at the end of life:		
No	**10**	**10.4**
Yes	**90**	**93.8**
Through experience/informal training	(81)	(84.4)
Through formal training	(9)	(9.4)
§Physician feeling of support by current protocols of care in Trinidad and Tobago preferred management and decision-making:		
No	**71**	**75.5**
Yes	**23**	**24.5**

***Total numbers represent death cases, hence, the same general practitioner might have reported on multiple cases (maximum of three cases per general practitioner).**
†Multiple answers possible, hence percentages do not add up to 100%.
‡An 'other' category was included as an answer option, however, responses (continuous medical education, conferences and workshops and seminars) suggested no formal palliative care training.
§2 missing.

GPs who had formal training in palliative care, either as part of their medical degree or through a postgraduate programme, were more likely to prescribe or administer opioids in the last seven-days of life 35.7% than those who had no formal training 11.1% ($p = 0.01$) (Table 4). In GPs with formal training, compared to those without, discussions with patients about withholding treatments (25% compared to 6.7%) and about giving medications to alleviate pain or symptoms were more likely to occur. Those without formal training tended more often not to discuss any treatment options (75.6% vs 39.3%, *p* = 0.002). The proportion of GPs who had palliative care training also had discussions with other caregivers about end-of-life treatment options more than GPs with no training (Table 4).

Table 2. Types and frequency of end-of-life decisions made by general practitioners for non-sudden deaths.

	Total (N = 73)	
End-of-life decisions	**N**	**%**
Medications administered in the last 7 days of life:		
No	25	34.2
*Yes	48	65.8
Morphine or other opioid	15	20.5
Diazepam or other benzodiazepine	13	17.8
Antiemetic	10	13.7
Laxative	9	12.3
Dopamine or other vasopressors	1	1.4
†Other	20	27.4
‡Influence on timing of death in the last 7 days of life:		
No influence on timing of death	48	65.8
Possibly delayed timing of death	12	16.4
Possibly brought forward timing of death	0	0
Certainly, brought forward timing of death	0	0
Treatments withdrawn	0	0
Treatments withheld:		
No	66	90.4
*Yes	7	9.6
Artificial hydration (intravenous line, subcutaneous)	5	6.8
Artificial nutrition (parenteral nutrition, P.E.G. tube)	5	6.8
Artificial ventilation (intubation or BPAP)	3	4.1
Cardio-pulmonary resuscitation	3	4.1
Antibiotics	2	2.7
Dialysis	2	2.7
Transfusion of blood products	2	2.7
Chemo-therapy or other cancer therapy	1	1.4
Surgery	1	1.4

***Multiple answers possible, hence percentages do not add up to 100%**
†Other medications include: nonsteroidal analgesics, antidiarrheal, antibiotics, steroids and vitamins
‡13 missing
Abbreviations: PEG – percutaneous endoscopic gastrostomy, BPAP – bilevel positive airway pressure

Table 3. Characteristics of end-of-life decision-making by general practitioners for non-sudden deaths.

	Total (N = 73)	
Decision-making	**N**	**%**
Discussion with patient on end-of-life treatment options		
No discussion	45	61.6
*Yes, discussed with patient	28	38.4
About giving medications to alleviate pain and/or symptoms	22	30.1
About withholding treatment(s)	10	13.7
About withdrawing treatment(s)	3	4.1
*Other caregivers included in discussions on end-of-life treatment options		
Patient's partner or relatives	55	75.3
Medical colleague/s	8	11.0
Nursing staff	6	8.2
Another caregiver	5	6.8
Patient request for hastened end-of-life		
No	57	78.1
*Yes	6	8.2
But not explicitly	4	5.5
Explicitly	2	2.7
I don't know	10	13.7

***Multiple answers possible, hence percentages do not add up to 100%**

Table 4. End-of-life decisions and decision-making for non-sudden deaths in relation to general practitioners' formal training in palliative care.

	Formal palliative care training				
	No		Yes		
Types of end-of-life decisions	n	%	n	%	P-value
Medications administered in the last 7 days of life:					
No medications were used to alleviate symptoms	17	37.8	8	28.6	0.42
*Yes, medications were used to alleviate symptoms					
Morphine or other opioid	5	11.1	10	35.7	**0.01**
Diazepam or other benzodiazepine	9	20.0	4	14.3	0.54
Dopamine or other vasopressors	0	0	1	3.6	†
Laxative	4	8.9	5	17.9	0.26
Antiemetic	5	11.1	5	17.9	0.41
‡Other	13	28.9	7	25.0	0.71
Treatments withheld:					
No	40	88.9	26	92.9	-
*Yes	5	11.1	2	7.1	-
Antibiotics	2	4.4	0	0	†
Artificial hydration (intravenous line, subcutaneous)	4	8.9	1	3.6	0.34
Artificial nutrition (parenteral nutrition, P.E.G. tube)	4	8.9	1	3.6	0.34
Artificial ventilation (intubation or BPAP)	2	4.4	1	3.6	0.52
Chemo-therapy or other cancer therapy	1	2.2	0	0	†
Dialysis	2	4.4	0	0	†
Transfusion of blood products	2	4.4	0	0	†
Cardio-pulmonary resuscitation	3	6.7	0	0	†
Surgery	1	2.2	0	0	†
Discussion with patient on end-of-life treatment options:					
No discussion	34	75.6	11	39.3	**0.002**
*Yes discussion					
About withholding treatment(s)	3	6.7	7	25.0	0.07
About withdrawing treatment(s)	0	0	3	10.7	†
About giving medications to alleviate pain and/or symptoms	8	17.8	14	50.0	**0.004**
*Discussion with other caregivers on end-of-life treatment options:					
Medical colleague/s	3	6.7	5	17.9	0.14
Nursing staff	3	6.7	3	10.7	0.54
Another caregiver	1	2.2	4	14.3	**0.05**
Patient's partner or relatives	31	68.9	24	85.7	0.11

***Multiple answers possible, hence percentages do not add up to 100%**
Percentages are column
†P-values could not be calculated due to empty cells
‡Other treatments include: nonsteroidal analgesics, antidiarrheal, antibiotics, steroids and vitamins
Abbreviations: PEG – percutaneous endoscopic gastrostomy, BPAP – bilevel positive airway pressure

DISCUSSION

Summary of main findings

This study provides the first data on MELDs on a representative sample of decedents who died at a private home with an end-of-life trajectory in Trinidad and Tobago. Our data shows that most GPs (69.8%) had no formal palliative care training, their expertise in end-of-life communication with their patients was self-taught and developed through experience over the years. The most prevalent MELDs were the administration of morphine or other opioid 20.5% and withholding artificial hydration and nutrition 6.8%. A large majority of GPs (61.6%) did not have any discussions with their patients on end-of-life treatment options but did include the patient's partner or relatives in discussions in most cases, (75.3%). GPs trained in palliative care were more likely to prescribe or administer opioids to their patients in the last seven-days of life, 35.7% (training) vs 11.1% (no training), and discuss with patients about giving medications to alleviate pain or symptoms, 50% (training) vs 17.8% (no training), than GPs without training.

Strengths and limitations

The mortality follow-back approach used in this study is an efficient means to collect national information and to describe the last days and months of life—a time when interviewing dying persons is sensitive, potentially inappropriate and logistically challenging.[24] A questionnaire was developed based on an existing validated questionnaire[4] and further validated in T&T for this study.[26] Our sampling frame was, (1:2), which is similar to that used in studies done in countries with advanced palliative and end-of-life care systems,[1,27] and improves the opportunity for comparison of our findings. Some study limitations include the drawbacks inherent to postal surveys like, recall and response bias[28] and our study cannot exclude such limitations. To mitigate this the lag between a death and the physician receiving a questionnaire was reasonably short at 3-months. A shorter delay could probably reduce possible recall bias but was not possible due to the time between death, medical certification and the receiving of the certificates at the CSO.

Despite a carefully applied Total Design Method including follow-up mailings[29] our response rate is low (31%) compared to similar studies in other countries.[1,27] Some possible reasons for the response rate include the efficiency of the postal service, unfamiliarity of GPs with this type of survey or mailing procedure, or it is possible that voluntary participation in postal surveys is not a cultural norm in T&T. Although our analysis of the non-response did indicate that the responding population is similar to the non-responding in terms of the known characteristics, we cannot exclude a selective non-response in terms of unknown characteristics. For instance, it is possible that our obtained sample is biased toward people who died with a clearer and more predictable end-of-life trajectory, and bias of GPs with an interest in the field of palliative medicine could have affected the responses. Also, the sensitive nature of questions could have affected physician self-reporting, as they may have felt they could not be truthful about their own end-of-life practices.[30] Additionally, selection bias due to sampling cannot be ruled out as incomplete information on some death certificates (for example, decedent age or sex were missing or the certifying GPs' name or contact details were illegible) excluded such cases.

INTERPRETATION OF THE RESULTS

The importance of provider education and training in palliative care can play a critical role in the quality, availability of and access to care, particularly in resource-poor countries where palliative care services are underdeveloped. Our study shows that relatively few GPs have any formal palliative care training and when compared to GPs without training, there is a notable difference in MELDs. For example, the former seem to give their patients morphine or other opioid to alleviate pain and symptoms in the last seven-days of life, or discuss with their patients end-of-life treatment options more frequently than GPs without training. A cross-national European study that looked at physician attitudes towards end-of-life discussions similarly found an association between palliative care training and their likelihood to discuss the potential life-shortening effect of treatments with patients.[31] In another study, palliative care experts, compared to non-experts, withheld artificial nutrition and/or hydration more often and were more inclusive of the patient or family in decision-making.[32] Unsurprisingly, this difference might be explained by the better understanding gained from postgraduate training in palliative and end-of-life care, which improved not only physicians' awareness of a problem and willingness to act but also their ability to optimally communicate to the benefit of the patient. GPs are the main source for formal palliative and end-of-life care provision in T&T reflecting their important role,[20] but to further develop a palliative care culture crucial steps, for example, compulsory formal postgraduate training may be needed to improve end-of-life care capacity and the manner of dying from a terminal illness.

GPs involved the patient in discussions on end-of-life treatment options in 38% of non-sudden death cases, which is higher than similar studies found in Spain (7%), Italy (10%), and Belgium (25%) but lower than in the Netherlands (47%).[33] The patient's partner or relatives were more often consulted in MELDs 75% and may reflect a societal norm of not openly discussing death and dying with patients as a means of maintaining hope,[34] or possibly because patients prefer not to receive bad news and physicians avoid giving it.[35] Further research is warranted to identify associated factors why patients are mostly excluded from MELDs.

Our survey data showed that non-treatment decisions occurred infrequently for home deaths, particularly those that may hasten death, and no life-prolonging treatments were reportedly withdrawn. Compared to a similar study of six western European countries where the average non-treatment decision to withhold treatment was (49%),[36] our proportion was low 9.6%. Although guidelines are ambiguous,[37] forgoing end-of-life treatments like artificial hydration or nutrition could be a cultural taboo in the Caribbean[38] and withholding treatments may be considered life-shortening by physicians and family members.[39,40] Evidence supports this notion as 40% of the goals of care in the last 30-days of non-sudden home deaths in T&T were to prolong life, maintain function, or even cure.[20]

CONCLUSION

This study suggests GP/patient discussions about end-of-life treatment options is uncommon but GPs trained in palliative care appear to share end-of-life decision-making. If they are to continue as the predominant formal care provider, they need appropriate training and policy makers must provide the necessary regulatory support to develop palliative care in Trinidad and Tobago.

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GENERAL DISCUSSION

8 Summary Of Main Findings, Methodological Considerations, Discussion And Conclusion

General Discussion

SUMMARY OF MAIN FINDINGS, METHODOLOGICAL CONSIDERATIONS, DISCUSSION AND CONCLUSION

8.1 INTRODUCTION

This **Chapter** concludes this thesis. We will summarise the main findings, outline the strengths and limitations of the methods used and reflect on lessons learned, and finally we consider the implications of our findings and offer some recommendations, in the context of a small resource-poor country, for advancing palliative care in relation to practice, policy and further research. It should be taken into consideration that the shared history and cultural backgrounds between Trinidad and Tobago, and other English-speaking Caribbean nations can mean that issues and challenges related to palliative and end-of-life care may be similar. Therefore, solutions may also be similar and progress on palliative care in one nation can be used as a framework for its intraregional development.

8.2 SUMMARY OF MAIN FINDINGS

PART I – IDENTIFYING KNOWLEDGE AND KNOWLEDGE GAPS IN THE LITERATURE

8.2.1 *REVIEW OF THE LITERATURE*

Chapter 2 served as a starting point for the thesis. In it we performed a scoping review in order to describe the state of knowledge as described in the published academic and grey literature on palliative and end-of-life care in English-speaking Caribbean nations, a group of resource-poor countries that share similar cultural and historical backgrounds, including similar economic, environmental and research challenges. A systematic search identified only twenty-five published articles that spanned the years 1991 to 2015, ten of which were original studies, reflecting the scarcity of (empirical) information that could be used to inform and guide public health practice regarding palliative and end-of-life care. We identified five important themes in the literature: 1) socioeconomic and cultural norms about terminal illness and death that influence the development and delivery of palliative and end-of-life care; 2) limited access to opioids for medical use; 3) limited palliative care services as compared to need; 4) unmet needs for palliative care; and 5) a lack of relevant research activity in the region. Some common barriers to the development of palliative care in the English-speaking Caribbean include: inadequate health care systems that deny universal health coverage and that offer few options regarding palliative care support services to patients with life-limiting or life-threatening conditions; an absence of documented policy and outdated beliefs on the effective use of opioid analgesics; limited awareness of and access to available palliative care services fosters unmet needs; poor communication between health care providers, patients and their family hinders accurate information sharing; cultural taboos and attitudes of the public toward terminal illness and death are strongly influenced by religious beliefs; and the absence of a research culture.

Opportunities to improve palliative care coverage and services in a resource-poor context were suggested for practice – cultivate existing cultural traditions of home care for the elderly by enabling a community lead approach of informal caregivers similar to the Neighbourhood Network in Palliative Care in Kerala, India (1); for policy – scale up existing guidelines for opioid pain management in oncology to include palliative care (2); and for research – to address the shortage of qualified researchers, integrate culturally relevant research methods training into existing curricula, e.g., at medical and nursing schools, and collaborate with foreign institutions capable of sharing their research expertise and infrastructure (3).

Compared to other developing countries in Latin America or Africa our findings were not unique since the lack of empirical information on the provision of and access to palliative care are common challenges in resource-poor countries and regions. However, our study identified opportunities for improvement in the English-speaking Caribbean for the overlapping issues of practice, policy, and research and offers a conceptual framework for further research.

PART II – USING AVAILABLE ADMINISTRATIVE AND ROUTINELY COLLECTED DATA TO DO POPULATION-LEVEL STUDIES IN RESOURCE-POOR CONTEXTS

8.2.2 *WHERE DO PEOPLE DIE IN TRINIDAD AND TOBAGO*

One of the main aims of palliative care is enabling choice about place of care and death, once quality of care is not compromised, the home environment is often the preferred place of death (4,5) as a home death is associated with a better quality of dying, and greater involvement of family and informal caregivers (6). In **Chapter 3** we analysed routinely collected death certificate data in Trinidad and Tobago. We obtained a dataset for the year 2010 from the national death registry. 2010 was the most recent available year at the time of the study. Supplementary health data was obtained from the Ministry of Health and included in our analyses. The largest proportion of deaths (55.4%) occurred in government hospitals; whilst (29.7%) occurred at a private home and (5.9%) in a nursing home or non-government (private) hospital. We observed that the place of death is influenced by age, underlying cause of death, sex, level of urbanisation and race/ethnicity.

Death at home becomes more likely with increasing age. Compared with the reference group those aged 18–69 it is more likely at ages 70–89 (OR 1.91, 95% CI 1.73 to 2.10) and age 90–highest (OR 3.63, 95% CI 3.08 to 4.27) to die at home. Home death was also more likely for those with diseases of the nervous system (OR 1.44, 95% CI 1.08 to 1.93) compared with the reference group, people dying from cardiovascular diseases, but less likely for people with cancer (OR 0.85, 95% CI 0.74 to 0.97), cerebrovascular disease (OR 0.61, 95% CI 0.51 to 0.72) or respiratory diseases (OR 0.74, 95% CI 0.59 to 0.91) than the reference group. We also observed that dying from diseases of the nervous system (OR 0.49, 95% CI 0.37 to 0.66) was associated with a lower chance of dying in a government hospital.

Compared to women men have a higher likelihood of dying at a government hospital (OR 0.87, 95% CI 0.80 to 0.94), and living in a rural area was associated with a higher likelihood of dying at home (OR 1.51, 95% CI 1.35 to 1.70) and a lower likelihood of dying in government hospital (OR 0.77, 95% CI 0.69 to 0.86).

Our reporting of the different ethnic groups is according to how this demographic is collected on death certificates. There appears to be inequality between ethnic groups regarding place of care and death since the place of death of people categorised as ethnically white is different from every other race/ethnic group as 48.8% died at home and 17.1% in a nursing home or private hospital, which was more than any other ethnic group, whereas 29.3% died at a government hospital, the least of any other group. A regression model with the variable race/ethnicity (61.1% of data were missing) as an independent variable, controlling for age, sex and cause of death, confirmed a significantly lower chance of dying at home for black (OR 0.51, 95% CI 0.27 to 0.98) than for ethnically white people and a larger chance of dying in hospital for East Indian (OR 2.32, 95% CI 1.14 to 4.71) and black (OR 3.33, 95% CI 1.64 to 6.74) compared with ethnically white people.

This study demonstrates that even in low-resourced environments, it may be possible to use death certificate and supplementary health data to study the place of death and variation in it according to sociodemographic and clinical characteristics. The findings suggest that attention is required in different care settings to monitor the availability, affordability and access to good end-of-life care but also for guaranteeing equity (e.g., by ethnic groups and clinical presentation) in these factors.

8.2.3 *THE PLACE OF DEATH OVER TIME*

In **Chapter 4** we further explored the secular trends in the place where people die since this can have important consequences for health care costs, including in small resource-poor countries, as end-of-life care in hospitals has been demonstrated to be more expensive than out-of-hospital care (7). Fully completed and reliable datasets were available for the years 1999 through 2010 where the total number of observed deaths were (N = 118,703). The three main recorded causes of death over this period, ranked according to frequency, were cardiovascular diseases, diabetes mellitus and malignancies. A subcategory of persons who died from some of the most common life-limiting conditions was considered. These included the following diseases and their corresponding International Classification of Diseases 10 (ICD10) coding: cardiovascular disease (I00–I52, I70–I99), cancer (C00–C97), respiratory disease (J00–J99), diseases of the nervous system (G00–G99), cerebrovascular disease (I60–I69) and diabetes mellitus (E08–E13).

The proportion of deaths from cancer increased in the period 1999-2010 and deaths from cardiovascular diseases decreased over time. We observed that the proportion of deaths in government hospitals sharply increased, from 48.9% in 1999 to 55.4% in 2010. However, the proportion of deaths in private homes strongly decreased from 38.7% to 29.7% in the same period. Over time, shifts in hospital and home deaths were even more striking for deaths that occurred from conditions that, according to operationalizations found in the literature, are indicative of palliative care need. Deaths from cancer were most noticeable where home deaths fell from 51.6% in 1999 to 31.2% in 2010 but hospital deaths increased from 38.4% to 54.7% during the same period.

The proportion of deaths occurring in a nursing home or private hospital decreased (7.1% to 5.9%), and deaths occurring in other places, inclusive of private geriatric homes, increased (5.3% to 8.9%). We compared observed and standardised (for age and sex) figures for the period 1999 to 2010 but observed little variation.

This study showed a strong ‘hospitalization of death’ trend, similar to the trends observed in many developed and high-resource countries in the second half of the 20th century (8-10). However, a reversal trend over the last two decades was observed where in many of those countries fewer in-hospital deaths occurred (11-17), and this has been related to palliative or end-of-life care strategies. Hence, the continuing trends in Trinidad and Tobago suggest a need for a national strategy on palliative and end-of-life care that acknowledges both the increasing number of people seeking care at government hospitals and that considers alternatives to accommodate out-of-hospital care and deaths.

PART III – GENERATING NEW DATA AND INVESTIGATING THE CIRCUMSTANCES OF END-OF-LIFE CARE AND DYING FROM SERIOUS ILLNESSES USING A MORTALITY FOLLOW-BACK STUDY

8.2.4 *QUESTIONNAIRE DEVELOPMENT FOR MORTALITY FOLLOW-BACK STUDIES*

As was identified in the scoping review of **Chapter 2**, there is need for reliable, culturally sensitive information on end-of-life care in developing and resource-poor countries. An important aim of this thesis was to make a contribution in addressing this need. We chose to conduct a population-based mortality follow-back study as this has been a major method to gather reliable information on end-of-life care in resource-rich countries. However, methods and instruments used in those countries cannot just be applied in a resource-poor country like Trinidad and Tobago and need adaptation for context and cultural sensitivity. Therefore, in **Chapter 5** we describe the development of a self-administered questionnaire (modelled on a validated questionnaire on end-of-life care and medical decision-making in the Netherlands)(18), to assess and document palliative and end-of-life care and medical decision-making at the end of life in Trinidad and Tobago.

The starting point was a questionnaire developed based on questionnaires used in resource-rich countries and on the findings from the scoping review of **Chapter 2**. The empirical material for this study mainly draws upon interviews that were carried out with 18 physicians with varying backgrounds including, general practitioners, oncologists, gerontologists, internal and palliative medicine clinicians. Fourteen physicians from Trinidad and four from Tobago, voluntarily participated in face-to-face interviews where we obtained face and content validity of the questionnaire. Some important changes to the initially proposed questionnaire included: the addition of a palliative care definition and instructions for completion; adjustments to question formulations, wording, sequence of questions, answer options and layout; and removal or addition of questions and answer options.

Our study demonstrates that despite challenges in doing public health related research in a resource-poor or developing country context, it is possible to use existing instruments from resource-rich countries. However, it is clearly important to make relevant sociocultural and clinical adaptations to the specific context.

8.2.5 *PALLIATIVE AND END-OF-LIFE CARE FOR PATIENTS DYING NON-SUDDENLY IN THE HOME SETTING*

The questionnaire developed in **Chapter 5** was then used in a population-based nationwide mortality follow-back study of home deaths certified by general practitioners. **Chapter 6** describes the findings from this study regarding the palliative and end-of-life care that patients with an end-of-life trajectory received prior to their death at home. We hypothesised the scenario that persons dying at home non-suddenly who could benefit from palliative care are not receiving it at an adequate level.

Three hundred and nine questionnaires representing 21% of recorded adult deaths that occurred at a private home and their death certificates available during the study period were mailed. The survey response rate was 31% (N = 96). Of these, 76% were non-sudden deaths but (27.4%) of people who died non-suddenly from conditions indicative of a palliative care need did not receive any palliative care. There were no significant differences for sex (P = 0.12), age (P = 0.62), or cause of death (P = 0.85) between the decedents in the response sample compared to all deaths surveyed.

Overall, the patient’s family members and general practitioner were the most involved caregivers. Family members provided palliative care in (60.3%) of the cases and exclusively in 22 (30%) cases. General practitioners were involved in care in (39.7%) of cases. Family members and general practitioners provide a large part of the care and play important roles for their dying relatives and patients regardless of the disease. Specialised palliative care services are not often used as only (6.8%) of patients received it prior to their deaths. In the last 30-days of life, however, apart from general practitioners, the caregivers most often involved in care were family members (89.0%), nurses (31.5%), and medical specialists (15.1%). Also, in the last 30-days of life, the most prevalent treatments included analgesics (53.4%), antibiotics (34.2%), and artificial hydration (26%).

Our examination of the differences in care and treatment between noncancer and cancer deaths found that in cancer cases, decedents received it mainly from family members (73.3%) followed by general practitioners (60%) and specialised palliative care services (13.3%). A greater proportion of deaths from cancer received analgesics (93.3%) than noncancer (43.9%) deaths, (P = 0.003). General practitioners prioritised comfort maximization (60.3%) as the main goal of care in the last week of life, and analgesics (53.4%) were the predominant treatment for achieving this goal.

Our study shows that informal caregivers, particularly family members, are most important in delivering palliative care to their terminally ill relatives in the community. Therefore, programmes to train family members to provide necessary end-of-life care are critically important particularly for resource-poor countries that lack trained professionals.

8.2.6 *MEDICAL END-OF-LIFE DECISION-MAKING IN NON-SUDDEN HOME DEATHS*

Chapter 7 describes the findings from the population-based nationwide mortality follow-back study about the care patients with an end-of-life trajectory received from their general practitioners, and the medical end-of-life decisions made prior to the patient's death at home. We conducted a nationwide postal-mail survey of general practitioners with the questionnaire we developed in **Chapter 5**.

Our data shows that most general practitioners (69.8%) had no formal palliative care training, i.e., either as part of their medical education or postgraduate education programme. Most considered that their expertise in end-of-life communication with their patients (78.1%) and patients' family members (84.4%) was self-taught and developed through experience over the years.

Most general practitioners (61.6%) did not have any discussions with their patients on end-of-life treatment options but the patient's partner or relatives were included in discussions in most cases (75.3%). However, when discussions included patients, the most common were about giving medications to alleviate pain and symptoms (30.1%), withholding treatments

(13.7%) or withdrawing treatments (4.1%). When general practitioners with formal training were compared to those without, we found that discussions with patients about withholding treatments (25% compared to 6.7%) and about giving medications to alleviate pain or symptoms were more likely to occur. Those without formal training more often tended not to discuss any treatment options (75.6% vs 39.3%, p = 0.002).

The most prevalent medical end-of-life decisions were the administration of morphine or other opioid (20.5%) and withholding artificial hydration and nutrition (6.8%). Of the non-treatment decisions, no treatments were withdrawn but life-prolonging treatments were withheld in 7 (9.6%) deaths. The most common withheld treatments were artificial hydration and artificial nutrition 6.8% followed by artificial ventilation and cardio-pulmonary resuscitation 4.1%.

In 34.2% of cases no medications were used to alleviate patient symptoms in the last seven-days of life, but Morphine or other opioids 20.5% and Diazepam or other benzodiazepines 17.8% were the most common medications given during this time. We found that general practitioners who had formal training in palliative care, either as part of their medical degree or through a postgraduate programme, were more likely to prescribe or administer opioids in the last seven-days of life 35.7% than those who had no formal training 11.1% (p = 0.01).

Our study shows that relatively few general practitioners have any formal palliative care training, but findings suggest an association between training in palliative care and the likelihood of treating patients with opioids at the end of life and discussing end-of-life treatment options with the patient and other caregivers.

8.3 METHODOLOGICAL CONSIDERATIONS

The research methods used in this document may not be considered cutting edge or unique since they were and continue to be used for similar population-based studies in North American, Western European and other industrialised regions of the world with developed palliative and end-of-life care service provision. However, for a small resource-poor country with a scarcity of information on how people are dying from terminal illness, where the need and type of care, and related services are not mapped, these robust research methods and concomitant studies can be considered pioneering for Trinidad and Tobago and the English-speaking Caribbean.

To answer the research questions of this dissertation, several study designs and data sources were used: (**Chapter 2**) was based on a scoping literature review of palliative and end-of-life care in the English-speaking Caribbean. A dataset containing routinely collected population-level administrative data, specifically death certificates, directed place of death studies in (**Chapter 3**) and (**Chapter 4**), this method allowed us to describe a population distribution for place of death and was the first time it was used in an English-speaking Caribbean nation. (**Chapter 5**) is based on a qualitative study that used face-to-face interviews for the development of a questionnaire for use in a national survey, and in (**Chapter 6**) and (**Chapter 7**) a mortality follow-back study was used to obtain data on palliative and end-of-life care and medical decision-making at the end of life, a novel method to conduct research in Trinidad and Tobago. The strengths and limitations of the studies will also be discussed in this chapter.

8.3.1 *REVIEW OF THE LITERATURE*

In developing and resource-poor countries, little information exists about the circumstances of dying from chronic and life-limiting conditions and important aspects surrounding palliative care needs of patients are under researched (7,19-21). To get a better understanding of all available published literature, peer-reviewed and grey, on palliative care in the English-speaking Caribbean, we conducted an internet and hand search for information. No date restrictions on publications were used. In consultations with research experts, relevant publications were identified for inclusion in the study and information was synthesised to the specific contexts for commonalities and themes about the topic.

A principal strength of a systematic scoping review and a reason why this method was preferred over a systematic literature review was the broad type of valuable information we could examine especially when information (empirical) about palliative care is scarce. This allowed us to rigorously explore and map in detail a wide range of literature – from lectures to reports – specifically concerning English-speaking Caribbean nations. We identified and clarified the complexity of core issues and at the same time envisage research gaps in the literature, challenges in the development of palliative care and possible innovative solutions (22,23).

There are several limitations to this study method. Our review was conducted in 2015 and was based on published information. At that time the small volume of literature on palliative and end-of-life care, particularly empirical studies, restricted our synthesis to the issues discussed in the information we reviewed. However, since then several original studies have been published all related to the role of palliative care in cancer (24-28), consequently the context and issues may have changed. It is possible that we may not have captured all the relevant issues pertaining to palliative care policy, education and training of care providers or the needed palliative care support services in the region.

8.3.2 *DEATH CERTIFICATES AND LINKED ADMINISTRATIVE INFORMATION*

Mortality data obtained from death certificates are widely used as information sources for epidemiologic studies, clinical investigations (estimating the burden of disease) (29), and for national statistics that can provide information on the efficiency of health care delivery (30). It is often the only source of regular information obtained systematically on a population, however, studies that use mortality data require timely access to such information.

Some distinct advantages of using population-level routinely collected data relate to their general availability (secondary data), and it can be a relatively low-cost source of information for researchers and policymakers including those in resource-poor and developing countries (31-33). Specifically in the end-of-life care context, primary data collection can be burdensome for patients and caregivers, but by using a retrospective design and data source (death certificates) researchers can avoid responder burden (33). Additionally, due to the large number of data there is opportunity to identify and isolate relatively rare causes of death (34), which would be more difficult using surveys or other data sources.

Death certificates and other routinely collected administrative information were used to study the place of death of persons in Trinidad and Tobago. By using death certificates, we were able to identify and include in our study a subpopulation of persons who died from non-sudden causes for the year 2010 (**Chapter 3**). The consistency of information on death certificates also allowed an opportunity to focus on other subpopulations who died from some of the most common chronic life-limiting conditions, and shifts in their place of death over time 1999 to 2010 (**Chapter 4**), (35,36). Completed death certificates can be a useful tool to assess national mortality as data are at the population-level. Patterns are described within the whole population and are not subject to selection bias such as in surveys or medical records studies of selected groups of patients (17,32,37,38,).

We were able to link the death certificate dataset to other national administrative information including, the level of urbanisation and the number of government hospital beds. We also linked one of the five Regional Health Authorities to the municipality of residence of the deceased, which provided an opportunity to associate sociodemographic factors with the place of death (39,40) namely, age, sex, underlying cause of death, urbanisation and race/ethnicity (**Chapter 3**). For countries that use a Standard International Classification of Diseases coding of causes of death, improves the possibility for cross-national comparison studies in the sociodemographic shifts in the place of death and associated consequences.

There are several limitations to this method. The main being issues concerning completion and accuracy of recording the cause of death (41). For example, information on the age or sex of a decedent was sometimes not recorded on death certificates. Inaccuracies of recording the cause of death can stem from the physician completing the form not having a comprehensive knowledge of the patient’s medical history (42) or they lack the necessary training (41,43). Such errors could lead to inappropriate public health interventions such as misappropriation of resources (44) and may contribute to death certification being limited in its use for population level research (32,45,46). Another limitation is availability of data as our two studies were restricted to the availability of fully completed mortality datasets. At the time our analyses were done, the year 2010 was the most recent year, (a 7-year lag), and our trend study was similarly affected as data were only available from the year 1999.

Trinidad and Tobago is a multicultural multi-ethnic society, but there are only four categories (black, mixed, white, Chinese) to identify a decedent's ethnicity. Our observation was this category is often omitted by physicians, possibly because they are unsure of how or unwilling to complete this section of the death certificate (**Chapter 3**). Also, options for selecting place of death are restricted to four categories, which groups together very diverse settings like; nursing homes, private hospitals, hospices and geriatric homes, accordingly; evaluating the type and quality of care in each of these settings is impeded (47). Moreover, in many countries where place of death is registered, relevant sociodemographic data like marital status and living arrangement, income bracket, educational level, and level of urbanisation of the usual place of residence of the deceased are all considered reliable predictors for place of death (32,48), but this information is not collected. Additionally, the inability to link socio-demographic data from a national census to a mortality database can limit the depth of this kind of research (49). Therefore, mortality statistics in the form of death certificate data, allow for breadth but not depth for purposes of research. This type of data can provide reliable information about patterns but may offer little about what underlies these patterns or the reasons for them. Nevertheless, they are a useful starting point for further research using other methods such as surveys and qualitative study designs.

8.3.3 *QUESTIONNAIRE DEVELOPMENT*

An effective way of obtaining information about the nature of care at the end of life including availability, access and quality, and the circumstances influencing medical end-of-life decisions is by population-wide monitoring using questionnaires supplemented by mortality data (50). Yet, all questionnaires traced in the literature were developed for developed countries, confirming the need for reliable, culturally sensitive information in a resource-poor context. This necessitated adapting an existing self-administered questionnaire (for face and content validity) on end-of-life care provision and medical decision-making for use in a population-based mortality follow-back survey. Purposive sampling was done to select participants. Our questionnaire was developed and validated using semi-structured face-to-face interviews, which are an effective means of detecting social cues like intonation and body language (51). Interviews were individually done with a heterogeneous sample of physicians that represented a range of medical specialties, to explore and understand their interpretation of the questions and evaluate their generated responses (52). Verbal probing was used to further stimulate conversations on issues regarding a word, phrase or concept (53). This strategy provided participants the opportunity and confidentiality to offer their unencumbered opinions about issues and questions in the draft questionnaire. After each interview when additional relevant feedback was obtained, incremental adjustments were made to the questionnaire and each new iteration was tested in successive interviews. An interview guide was specifically developed for this study to systematise the process, and together with the questionnaire were used as triggers to elicit participant discussion. Participant semantic interpretations of the questions in the questionnaire conveys the cultural context of Trinidad and Tobago, consequently, the questionnaire could be readily used with minimal concern for sensitivity and semantics.

A limitation is the small sample typically targeted in cognitively testing questionnaires (53), which presents the possibility that some perspectives existing among physicians were not included in this study. Although representativeness for the physician population was not a criterion (as our aim was variation in their perspectives), it is possible that the physicians interviewed overrepresented those that have some palliative care training or were interested in the topic. Physicians were interviewed in their offices, clinical settings or other mutually agreed locations, as a result some interviews were rushed because they had to return to their clinical duties and information transfer may have been less effective.

8.3.4 *MORTALITY FOLLOW-BACK STUDY*

The mortality follow-back study on end-of-life care and medical end-of-life decisions used in (**Chapter 6**) and (**Chapter 7**) is an efficient means to collect national information and establish findings at a population level, which is well suited in a resource-poor context where national data is lacking. Through a retrospective design, the last days and months of life, a time when interviewing dying persons is sensitive, potentially inappropriate and logistically challenging can be described regardless of whether a person was identified as terminally ill or end-of-life care was intended (33). Therefore, a retrospective design allows for a random sample of deaths where information can be generalisable toward the entire population of deaths. This avoids issues of selection bias compared to focusing on a population that is prospectively defined in terms of their being identified as ‘end-of-life’ or as users of formal palliative and end-of-life care (54). It is particularly important for Trinidad and Tobago, where the availability of formal palliative care is limited and uptake of care is unknown, to also capture and not exclude people who are not receiving formal palliative and end-of-life care (55). Other advantages are related to a reduction of recall bias, for example, physicians were asked to respond about deceased persons, and based on their death certificates, physicians are allowed the opportunity to refer to the patient’s medical records. It is important to note, however, a debate about the usefulness of retrospective designs between Bach et al (56), and Teno and Mor (57). Bach and colleagues consider retrospective studies, i.e., ‘studies of decedents’, to less accurately account for the care provided to patients prior to their deaths than prospective studies. In our case and other similar cases of countries or regions being resource-poor, where the circumstances of dying from a chronic condition is largely unknown at the population-level, data from a relatively inexpensive study method (retrospective) can be a valuable resource. It can be a starting point to better understand the care needs of patients and the support their family members and carers may require to improve care, which can then be followed up with further research.

For our study a random sample of persons aged 18 years or older, who were Trinidad and Tobago residents, and died at a private home in 2018, was drawn from the death certificates at the national death registry the Central Statistical Office. The sampling frame was obtained from death certificates which was (1:2), similar to studies in countries with advanced palliative and end-of-life care systems (58,59), which improves the opportunity for comparison of our findings. To maintain anonymity of general practitioners and guarantee that completed questionnaires could never be linked to a particular patient or physician, a neutral party (Trinidad and Tobago Medical Association), was involved in the mailing procedure for the national survey. This agency acted as an intermediary between responding general practitioners, researchers, and the Central Statistical Office.

There are also limitations to this method. Our study cannot exclude inherent drawbacks to postal surveys like, recall and response bias (60). A 3-month lag between a death and the physician receiving a questionnaire was used to mitigate bias. The response rate was 31% although a carefully applied Total Design Method including follow-up mailings was used (61). The response rate could be related to the efficiency of the postal service, unfamiliarity of physicians with this type of survey or mailing procedure, or it is possible that voluntary participation in postal surveys is not a cultural norm in Trinidad and Tobago.

Known characteristics of the non-responding and responding populations were similar, however, we cannot exclude a selective non-response in terms of unknown characteristics. For instance, it is possible that our obtained sample is biased toward people who died with a clearer and more predictable end-of-life trajectory, and bias of physicians with an interest in the field of palliative medicine could have affected the responses. Also, the sensitive nature of questions could have affected physician self-reporting, as they may have felt they could not be truthful about their own end-of-life practices (62). Additionally, death certificates are paper-based and contain demographic information – sex, age, usual place of residence, date, and cause of death – of a decedent including the name and professional address of the certifying physician. Some selection bias due to the sampling cannot be ruled out as, due to incomplete information on some death certificates (e.g., decedent age or sex were missing or the certifying physician's handwritten name, contact details or information on the decedent were illegible) some cases could not be included in the sample.

8.4 LESSONS LEARNED

This section reflects on and relates to personal experiences and issues I encountered. Local colleagues in Trinidad and Tobago expressed surprise that we negotiated with the Central Statistical Office to allow access to mortality data sets and to sample death certificates for a six-month period for the mortality follow-back study. My response was, *we approached the then acting director of the agency with our study protocol that outlined the data collection procedure and we assured him that the process will not impinge on the workflow nor burden the department staff with additional duties*. It is possible that my collaboration with the two foreign universities, Vrije Universiteit Brussel and St. George's University in Grenada, could have also had a positive influence in the matter. However, I was required to swear to a justice of the peace at a Magistrates' Court an '*Oath of Secrecy*' before I was allowed access to data at the Central Statistical Office.

Our study protocol described a framework for a descriptive mortality follow-back project on end-of-life care and medical end-of-life decisions, (**Chapter 6)** and **(Chapter 7)**, aimed to generate information on patients (e.g., age, sex, gender, cause of death, treatment received) and the characteristics of care at the end stage of their lives, including the medical end-of-life decisions made with their physicians (general practitioner and clinical specialist). The development of a culturally appropriate questionnaire, (**Chapter 5)**, for use in a national survey was central to the implementation of the retrospective study.

However, during our data collection we encountered some challenges which necessitated adjustments to our original research plans. Whilst our challenges may not be unique when doing a research project, they may be considered a normal occurrence or consequence of doing research in a small resource-poor developing country where a research culture is lacking. By research culture we mean, "*a culture which embraces the expectation that everyday health and social care should be based upon the best available knowledge or research findings rather than custom and practice, requiring that all professionals are critical consumers of research*" (63). The following section describes the main reasons why adjustments were made to our research protocol and data collection, but also hints to insights and considerations for future health care research in Trinidad and Tobago.

8.4.1 *QUESTIONNAIRE DEVELOPMENT*

We had an initial meeting with representatives from the Trinidad and Tobago Medical Association (T&TMA), a professional non-governmental organization with the mission to promote the medical and allied sciences, and maintain the honour and interest of the medical profession (64). Our planning meeting was to gain their support for the study in the role of a neutral partner, but also to get a better understanding of how physicians might react to such a questionnaire and national survey. From my personal assumptions and guidance offered by the medical association that physicians might be 'questionnaire averse', I was unsure how this necessary but uncharted process was going to unfold. Particularly since my profession is not a medical practitioner but my task was to interview physicians to get their candid views and practice of palliative and end-of-life care. It was during interviews, I observed that most physicians were surprised (some suspicious) and some intrigued that such a project was being undertaken. The consensus was that improvements in medical practice at the individual and policy levels and better patient outcomes were needed and long overdue, as they knew first-hand the burden of chronic disease on the population.

The T&TMA also urged us to minimize the length of our questionnaire and ideally keep it to one page as physicians may be, not only unfamiliar with the study design, but also less likely to respond if the questionnaire was any longer than one page. Although we attempted to adhere to this recommendation our goal was to obtain information about the care and treatment decedents received prior to death, and this required some investigation. I also observed during cognitive interviews that many physicians had difficulty with questions in which the term palliative care was used, (three questions specifically mentioned palliative care). They requested clarity about the type of care they were being asked to respond to. Therefore, a relatable definition was included, one that physicians agreed better described the dimensions of care they were likely to have encountered during their clinical practice in Trinidad and Tobago; i.e., ''*care that helps people live their life as fully and as comfortably as possible when living with a terminal illness. It identifies and treats symptoms which may be physical, emotional, spiritual, or social*'' (65). In the end physicians who were interviewed to develop our questionnaire were supportive of the project. Our questionnaire developed into a four-page document, the cover page with instructions for completion, two pages that focused on the patient's care and treatment, and one page that asked for sociodemographic information about the responding physician.

8.4.2 *NATIONAL SURVEY*

This study could not have been done without partnering with the T&TMA. Their enthusiasm about the prospects of such a project was infectious, and their insights and guidance enabled us to avoid potential obstacles. Importantly, their assistance with the management and coordination of the completed questionnaires and recording information into a questionnaire database were indispensable. Our survey method was modelled on a previous study done in Belgium (66). In that case the services of a lawyer was utilised as a trusted third party. This was done to safeguard anonymity of sensitive information on death certificates and physician questionnaires. In our case, to save on research costs (given the very limited research budget) and gain the confidence of physicians responding to a questionnaire, we requested and received the services of the T&TMA. Nevertheless, our response rate was 31%, low compared to other similar studies (58,59,67) in countries with developed palliative care services. Even so, there were no available similar national (indigenous) studies to compare our rate. Evidently, we were advised by the T&TMA not to anticipate a high response rate as previous surveys they did among their members about internal matters had an average yielded of 6%.

We also did a non-response survey that yielded only 5%. The two main reasons cited by physicians for not participating in the national survey were, they could not identify the patient with the data provided in the accompanying letter with the questionnaire, and the physician was not the treating physician of the patient in question. Our survey procedure, (**Chapter 6**), was rigorous with safeguards to protect patient and physician information. We also used the services of courier mail, which was more expensive than regular postal mail but we believed might improve the likelihood that our questionnaires were delivered to their respective destinations in a timely manner. Courier mail also proved useful when the questionnaire was undeliverable, i.e., the addressee could not be located. Although not many, the courier service returned these ‘return to sender’ questionnaire packages to the researcher who either verified the accuracy of the address and re-sent it or resampled the case according to protocol measures. Overall, the relative low survey response could be related to and include, the novelty of this type of study and mailing procedure and the lack of a research culture in Trinidad and Tobago.

8.4.3 *MORTALITY FOLLOW-BACK DESIGN FOR HOME DEATHS*

We encountered several issues during death certificate data collection. Early on, we noticed that community based primary care physicians such as district medical officers and community medical officers of health (who are physicians with public health duties and assigned to a particular regional geographic location) were completing a lot of certificates, often without having access to the decedent's medical history or notes. For the completion of the death certificate these physicians relied on information obtained from family members' knowledge of the patient before his/her death. We felt that inclusion of these certificates and subsequent sending of a questionnaire about the end-of-life care to the certifying physician (in these cases) would not lead to reliable knowledge about decedents in their terminal phase and made the decision to exclude accordingly. It is likely that these excluded cases could be persons who died suddenly and who were not under medical management of a particular physician, and therefore less likely to have had access to or received end-of-life care. Therefore, this necessitated a change in our research protocol where sampled death certificates completed by community based primary care physicians were excluded from the sample and the sample was limited to home deaths certified by general practitioners. Also, a 2-month lag in processing of death records necessitated a delay in our data collection, i.e., sampling deaths and mailing questionnaires, and due to a mail delay, it became necessary to extend the survey period by one month as there was a delivery backlog of completed questionnaires to the medical association.

In the context of Trinidad and Tobago, a mortality follow-back design to survey physicians presented some challenges but we also obtained useful information on the characteristics of patients, with end-of-life trajectories, and about medical treatments and end-of-life decision-making. In this case, the information we sort could only be provided by physicians, however, to help build a more complete picture it may be worth including family members as an information source for further research on palliative and end-of-life care at the home setting. Afterall, our study (**Chapter 6**) did indicate that family members were the main care providers for their dying loved ones and they may be better positioned to provide important information that physicians cannot. A mortality follow-back study involving informal carers, including family members, may pose different challenges but is certainly feasible considering hurdles already overcome.

8.4.4 *MORTALITY FOLLOW-BACK DESIGN FOR HOSPITAL DEATHS*

Our intended aim for the mortality follow-back study was to get an understanding about the differences in palliative care between the private home and government hospital settings. Our study protocol consisted of two concurrent surveys, a representative sample of home deaths and a study at a public hospital. To test the feasibility of doing such a study at a hospital, we considered a pilot study where we would sample deaths at the hospital instead of at the national death registry. This became necessary as we anticipated challenges with not only the timely mailed delivery of questionnaires to physicians at the hospital but also delivery of questionnaires to physicians at their respective departments. Therefore, using the same sampling procedure as we did for home deaths, we sampled death certificates at the main government hospital located in the North-Central Regional Health Authority (NCRHA). Weekly samples were made at the medical records department and a questionnaire package, addressed to the certifying physician, was left at the administrative office of respective departments.

To promote our study at the hospital, we embarked on several sensitization activities. Firstly, I had separate face-to-face meetings with the medical and surgical heads of department to describe the data collection process (sampling of death certificates and completion of questionnaires by physicians), and to get a sense of the level of their support for the project. An abridged version of the study protocol was offered and left with each department head. Secondly, this hospital organised weekly interdepartmental case study teaching sessions. Early in our data collection process I was invited to speak at a session where I introduced the study and process to physicians in attendance; this was done twice. Thirdly, I made weekly visits to the departments of the different administrative assistants (medical, surgical and medical records) to check on the uptake of questionnaires by physicians, and solicited suggestions from them on how to better coordinate between the departments and motivate physicians to complete the questionnaires.

However, numerous structural barriers at the hospital setting complicated data collection including: the medical records department being unable to locate patient files upon physician request, which delayed or interrupted the time physicians had allotted to complete the questionnaire; physicians not responding or not being able to respond to repeated requests by researchers to complete the questionnaire because of time constraints, i.e., attending to more urgent duties; and at this hospital there was a high turnover of physicians between departments and from the hospital. Consequently, repeated requests to physicians to complete the questionnaire were left undelivered and unanswered. Although we sampled weekly to minimize the time lag (and recall bias) between the death and the time the physician received a questionnaire about the corresponding death, it became increasingly challenging and impractical to continue this arm of the study, and we therefore decided to focus only on home deaths. It is possible that the circumstances encountered at this government hospital is similar to conditions in other similar hospitals in Trinidad and Tobago, and other resource-poor countries in the region.

A mortality follow-back design may be well suited for a hospital setting but will require teamwork from all parties. Physicians will need to be well aware of such a study and questionnaire packages will need to be available on participating hospital wards. Upon certifying a death, the physician with the patient's notes in hand, can complete the questionnaire and deliver it to a central location at the hospital where the mail service can then collect it. Our studies on place of death (**Chapter 3**) and (**Chapter 4**) indicated that most deaths occur at a government hospital and it is possible that patients who died there receive much more formal care and treatment than those who died at home, but their circumstances of dying have yet to be understood and explained.

8.5 DISCUSSION OF FINDINGS

8.5.1 *LIMITED PALLIATIVE CARE SERVICES*

Limited palliative and end-of-life care services in Trinidad and Tobago is a common theme across our studies and appears to be a shared challenge with other Caribbean countries (21,24,25). Central to this challenge is the increasing need for appropriate health care services to address the prevalence of people living with serious life-threatening or life-limiting illnesses. Coupled with aging populations suffering with a range of chronic comorbid conditions, dying from serious illnesses can become a burden on a country's health system (68). This scenario can affect high-income developed countries as well as developing and resource-poor countries. A starting point for service provision can be knowledge about the amount of need in relation to the conditions that cause serious health related suffering indicative of a palliative care need, namely; cardiovascular diseases, cancer, diabetes mellitus, chronic lung diseases, and neurodegenerative disorders (69). However, along with the management of physical symptoms of the condition the relief of psychological distress and support for informal caregivers such as family are inclusive of the palliative care needs (70).

There are few options for formal palliative care delivery. The two available community services (one in the Tobago RHA and the other in the eastern Trinidad RHA) are nurse lead, small and susceptible to disruptions in service due to stockout on medications or vehicles unavailable to transport staff to patient's homes. Importantly, a lack of skilled available nurses can certainly affect services particularly when a nurse retires as there is a time gap before a replacement can be found. Other services include the 12-bed government run outpatient unit in the north-central (RHA) and the two 12-bed inpatient non-governmental hospices in the northern (RHA). In relation to the number of people with chronic medical conditions we can conclude that the current service provision falls short.

8.5.2 *SETTINGS OF END-OF-LIFE CARE*

We explored the place of death across different settings in, (**Chapter 3**) and (**Chapter 4**), which included; government hospitals, private homes, nursing home or non-government hospitals and geriatric homes, and in (**Chapter 6**) and (**Chapter 7**) we specifically explored the private home setting. The aging demographic of the Trinidad and Tobago population, which was estimated at 1.4 million in 2019, becomes apparent when 18.2% was 60 years and older, but these figures are anticipated to increase to 24.5% and 36.5% by 2030 and 2050 respectively (71). High prevalence rates for life-limiting and life-threatening conditions including, cardiovascular diseases 33%, cancers 15%, diabetes mellitus 15% and chronic respiratory diseases 3% were among the main causes of serious health related suffering and death (72), and all are medical conditions indicative of palliative care need (73). The range of care will vary according to the need, but it appears the health care system will increasingly be challenged to provide palliative care across different institutions and settings in the foreseeable future.

It appears that resources are concentrated in government hospital settings and little attention and resources are focused elsewhere. Across all settings, the financial costs of care at the end of life can be substantial (74-76), but hospital care, particularly acute care, has been demonstrated to be more expensive than out-of-hospital care (7,77,78). Services and care at geriatric homes or assisted living facilities are unexplored at this time but our place of death trend study, (**Chapter 7**), indicated that the number of deaths at this setting is increasing. This scenario illustrates the need for widely accessible palliative care services that are integrated into the health care system according to an appropriate model, for example, a palliative care unit at each main government hospital, or care in the community which will include home care, or a combination of both. Nevertheless, urgent attention from policy makers and government health care decision-makers is needed.

8.5.3 *ROLE OF INFORMAL CARE*

Our place of death studies, (**Chapter 3**) and (**Chapter 4**), indicated that the majority of deaths including those indicative of a palliative care need, occurred outside of a private home. In fact, a majority of deaths were at a government hospital but the prevalence and type of palliative care received by those who needed it is unknown. In other words, government hospitals may not be the preferred place to receive palliative and end-of-life care. But due to a lack of options, the perception by those needing care may be that government hospitals are the only settings that can provide the level of care that is expected (79). Although our findings were calculated on data dated 2010 and before, we might assume that a significant number of deaths do still occur in a private home. With the few and limited services available the challenge of how to provide palliative and end-of-life care to those needing it in the home setting remains an irresolute issue.

Of all deaths worldwide it is estimated that palliative care could be beneficial for up to 74% of those who had a life-limiting or life-threatening condition (80), but where existing formal palliative care services are falling short, there is opportunity for care provided by informal caregivers. By informal caregiver we mean someone who provides or arranges unpaid assistance to a loved one, relative, friend or stranger (volunteer) because illness or disability rendered them incapable of selfcare (81). Informal caregivers, particularly family members, of persons with life-limiting or life-threatening conditions are important contributors of care. Their involvement can improve the overall quality of life of their loved ones by enabling activities of daily living such as; eating, hygiene and grooming or by offering emotional support. Their important role as front-line carers is evident as they are the ones giving medications (once trained to do so), e.g., for pain, and monitoring its effectiveness by observing for signs of undertreatment, or are acting as care coordinator and communicator between the patient and health care providers about the patient's condition (82-86). Additionally, palliative home care appears to positively impact quality outcomes for patients including reduced symptom burden (87), improved care quality and reduced end-of-life health care costs (88).

Data on the practice of informal caregiving, including the caregiver's knowledge and experience in providing safe and competent care, how they can access available support services that may assist them caring for loved ones, but importantly, carer support services that address the intense physical, emotional, psychological and in some cases financial toll of providing care to a family member or loved one are absent in the Trinidad and Tobago context. However, research found that costs borne by patients and their family caregivers or informal care costs (89), can contribute significantly to the overall cost of care (90,91), where for example in Canada, up to 76.7% of the full economic cost of palliative care was borne by patients' caregivers in the form of unpaid care (82), or in Ireland during the last year of life informal care costs accounted for more than 22% (92) and in Finland 27% (93). In some countries with developed and integrated palliative care services, family carers can claim time off from work, without loss of salary, to care for a family member or benefit from other social services that assist in the provision of care, and when professional medical or nursing care is needed part of these costs are subsidised by national insurance schemes (94-96).

In developing and resource-poor countries that have underdeveloped palliative care services and where the safety net of a responsive social welfare system may not be available, viable and alternative solutions of advancing palliative care must be explored. The grassroots public health approach to palliative care in the Indian state of Kerala, which utilises models of community participation, and where services are community-funded and supported in part by volunteerism may be an appropriate model to replicate. It facilitates home care and supports family carers, emphasises social and emotional well-being, operates within a community with community resources with an aim of building community capacity, and operates in collaboration with formal state health care providers (1). This indicates that the need for, and role of formal palliative and end-of-life care services should not be substituted. Even if funding towards such a compassionate community model were to substantially increase, thereby increasing service provision, it still may not fully address the majority of palliative and end-of-life care needs of patients or their family members. Therefore, a public health model, one that incorporates components of specialist and generalist palliative care services together with communities and neighbourhoods and civic palliative care programmes can be considered (97). To some degree elements of these components may already exist in communities in Trinidad and Tobago, and it is through the community structures that national health services have a responsibility to facilitate community empowerment and fulfil the functions of a public health model to palliative and end-of-life care.

8.5.4 *DOING HEALTH RESEARCH IN THE CARIBBEAN*

This section speaks directly to the nature of doing health research specifically in Trinidad and Tobago and generally in the English-speaking Caribbean. An understanding of the bureaucratic societal and organisational culture can help the researcher navigate the challenging and hurdle-filled process of doing health research in this region. The cultural *modus operandi* of how things are done is likely linked to the Caribbean's colonial legacy. I am hopeful that my experiences and suggestions may encourage further public health and palliative care research. As a national of Trinidad and Tobago I can say with some confidence that the societal and organisational culture of this small country is conservative, formal and pyramidal or top-down. This is by no means a judgment but merely an observation that can affect the undertaking of research projects. In contrast, my experience and interaction with supervisors and colleagues at End-of-Life Care Research Group department at Vrije Universiteit Brussel was different. Power distance between senior and junior personnel was not obvious, and staff addressed each other by their first names but importantly there was two-way communication.

Hofstede (2011) considers societal culture as an unconscious set of values, with tendencies to prefer certain states of affairs over others, and organisational culture as an often-visible perception of the environment within an organisation (98). He further identifies six dimensions to define and describe organisational culture which can be characterised as formal or informal. Formal cultures tend to be process-oriented as opposed to results-oriented, and be dominated by technical and bureaucratic routines with vast differences in perception among different levels and parts of a unit. Job-oriented as opposed to employee-oriented, where managers only assume responsibility for an employees' job performance and not the wellbeing of the employee. Professional instead of parochial, where members identify primarily with their profession as opposed to identity from their organisation. Formal organisational cultures have a closed communication system with reluctance to admit outsiders and newcomers into a unit. Tight control expresses the degree of formality and punctuality within the organisation, and finally the prevailing way of dealing with the environment is considered to be normative or rigid instead of pragmatic and flexible (98,99).

My experiences are pertinent to this description of a formal culture as I observed varying degrees of it during my engagement with different government departments, to request access to data and permission to do studies at government offices, e.g., the hospital arm of the mortality follow-back study. Apart from requesting and receiving ethics approval it was necessary to write letters of request to the Minister of Health and the Chief Executive Officer of the Regional Health Authority where the hospital is located. A letter of intent was written to the head of the medical records department at the hospital which was followed by a face-to-face meeting, and I had several meetings with the medical and surgical heads of staff including their executive assistants. This circumstance demanded preparation and persistence but yet may not be unique to the Caribbean. Despite these, what might be considered necessary formalities, it is also thanks to the cooperation of government authorities, and enthusiasm of the people whom we collaboration that these projects could be done.

The relative limited availability of PhD programmes, for example, to explore palliative and end-of-life care could well contribute to research being considered a novelty or luxury activity. This of course can be a barrier, in and of itself, to doing research in the Caribbean. If it exists, a research community of peers that focuses on the same study topic is not in clear view, which was the main reason for my enrolment in the Vrije Universiteit Brussel's End-of-Life Care Research Group programme in collaboration with St. George's University. Possibly in the coming years, more opportunities may become available to researchers in the Caribbean to collaborate with a wider scope of researchers or research groups regionally and internationally.

8.5.5 *BIOETHICS AND PALLIATIVE CARE IN THE CARIBBEAN*

According to the World Health Organisation, "*all people have the right to receive high quality care during serious illness and to a dignified death free of overwhelming pain and in line with their spiritual and religious needs*" (100). Therefore, access to health care (palliative care) moves from being political and legal issues to an ethical one where people with life-threatening or life-limiting conditions are afforded a reasonable and proportionate response to their needs, [i.e., "*something without which someone will be fundamentally harmed*" (101)] including, respect for their personal values, effective symptom management and psychosocial support, and having a say about their treatment and the medical decisions made (102). These and other considerations are imbedded in health care ethics popularised by philosophers Beauchamp and Childress (101) as *Principlism,* which are four core moral principles that can serve as action guides to ethical decisions in clinical medicine. *Autonomy* empowers the patient to make their own decisions about their body based on the patient's own value system, and is the basis for the practice of informed consent. *Beneficence* or relieving, lessening, or preventing harm. *Nonmaleficence* or avoidance of causing harm, and *Justice* or the impartial treatment of patients. These principles can provide a theoretical foundation for health care providers when faced with complex and competing interests involving palliative and end-of-life care for their patients (103).

Health care providers, particularly physicians, can routinely encounter a range of ethical issues when providing care to their patients, i.e., situations involving conflict about what should be done (104) or decisions that involves competing values (105). Broader palliative and end-of-life care ethical issues can include patient confidentiality and competence, resource allocation, advance directives, euthanasia and physician assisted suicide, or power of attorney (106). Some of which are reflected in the preceding pages of this thesis, e.g., issues related to access to palliative care including the availability and effective use of opioids for pain management (**Chapters 2, 3, 4, 6 and 7**), patient's autonomy and their inclusion in decision-making regarding their care and treatment, and the withholding or withdrawing of medical treatments including artificial nutrition and hydration during the last weeks or days of life (**Chapter 6**) and (**Chapter 7**) were among the ethical issues described. It is important then that health care provides possess a basic understanding about the scope of their practice in relation to ethical principles and are aware and capable of sensitively managing ethical issues, which can be considered a standard for quality of care.

In the English-speaking Caribbean little is written about the role and extent bioethical principles can influence the provision of health care. Findings from a study done at the main public sector hospital in Barbados suggested that physicians and nurses lack knowledge and awareness of not only the practical application of bioethics and its relevance to their practice, but also the extent to which they know and engage with the law (107). This is significant because inadequate knowledge and understanding of a moral framework to govern the behavioural norms for biomedical professional ethics, or compliance with laws or regulations can compromise patient care and put health care providers at legal risk (108). In (**Chapter 2**) it was indicated that social, cultural, political, and technological developments have influenced the attitudes, values and beliefs around end-of-life care in the English-speaking Caribbean, but these drivers have also shaped the role bioethics plays in the provision of care. The mutual mistrust described between health care providers and the public and the belief by some that physicians are unwilling to be truthful when discussing negative diagnoses can be indicative of the physician’s traditional paternalistic role of ‘doctor knows best’ which is in stark contrast to shared decision-making which involves the patient and respect for her/his autonomy (103).

In the Trinidad and Tobago context, a hospitalisation of death was described in (**Chapter 3**) and (**Chapter 4**) where a majority of patients seeking palliative care rely on institutionalised government settings. This is due to a number of reasons including the structure of the public health care system that requires no out-of-pocket payment at the point of service and the public perception that institutional professional care can better manage with the range of complex symptoms and needs of patients. Due to improvements in medical technology and practice in some settings, e.g., hospital intensive care units, the imperative of doing everything medically possible to prolong life, which can include artificial respiration on a mechanical ventilator, despite any meaningful health benefit to the patient may be considered, non-beneficial or even potentially inappropriate (109-111). Such actions can potentially expose the patient to considerable suffering including a loss of dignity which can constitute to doing harm to the patient regardless of the stage of their end-of-life trajectory (103). Moreover, the economic cost of providing care and treatment to patients deemed non-beneficial, particularly in an intensive care unit setting, may also be considered an ethically inappropriate use of scarce health care resources that may be put to beneficial use elsewhere in the health care system, e.g., antenatal care for women in underserved communities (112). However, physicians and nurses are legally obligated to provide treatment until the patient recovers, is medically certified as brain-dead or dies. The critical role general practitioners play in the provision of end-of-life care is described in (**Chapter 6**) and (**Chapter 7**), as they are the main formal health care providers for their patients who died at home, but their legal role is less recognised and may also be less understood (113).

In their clinical practice health care providers make ethical decisions every day, it is important that they are not only aware of this but are professionally and culturally prepared to make competent decisions. At some public sector hospitals in the English-speaking Caribbean medical/surgical departments hold a weekly review session. This is often an opportunity for junior doctors to present a patient case they experienced, (e.g., a patient case history including medical interventions and patient outcomes), and is a practical way to receive constructive feedback from their colleagues and senior medical staff (consultant physicians). These teaching and learning sessions are also an excellent opportunity to identify and explore bioethical issues, to reinforce clinicians' bioethical knowledge and practice or correct misunderstood principles. Such sessions can be used as continuing bioethical education for all levels of medical and nursing staff and can also be extended to other hospital departments such as pharmacy or hospital management and administration. Medical and nursing students should also be exposed to these or similar sessions which can be integrated into their respective curricula. Also, general practitioners should be required to partake in ongoing bioethical education which can be accessed via the internet. When health care providers are faced with an ethical dilemma there may often be no one good solution, but it is good if they can identify and are prepared to act on the least bad option (103).

8.6 IMPLICATIONS OF THIS DISSERTATION

This document concerns empirical evidence on palliative and end-of-life care in Trinidad and Tobago, some of the studies and methods used were the first of their kind in the English-speaking Caribbean. We explored some fundamental aspects of current issues, highlighted some challenges but also offered several suggestions for the integration into the health system and further development of palliative care. In this section, we offer some recommendations for practice, policy and further research in the Trinidad and Tobago context.

8.6.1 *RECOMMENDATIONS FOR PRACTICE*

A major barrier to the further development and expansion of palliative and end-of-life care services is the lack of trained health care providers, e.g., physicians, nurses, social workers, and other allied health disciplines, in palliative medicine (114).

8.6.1.1 *EDUCATION AND TRAINING: FORMAL CARERS*

Our findings, (**Chapter 7**), suggest that few general practitioners (who are the primary formal care providers) have any basic formal training in palliative medicine, and there are even fewer specialist physicians. Further revelations indicated that care differed between general practitioners with training as they appeared to be proactive when communicating with the patient and patient's family or with other caregivers, and they gave opioid medications for pain management more often than those without training. The avoidance of opioids used for pain management is prevalent in developing as well as developed countries (115-122) and can be linked to limited or outdated knowledge and education of their safe and effective use (123,124). The recognition of palliative medicine and palliative care by medical, nursing and allied health boards is needed to broaden the knowledge base and widen coverage (125). An example from Uganda's "training in morphine prescription" requires consideration. Uganda was the first country in Africa to allow health workers other than physicians to prescribe morphine. A nine-month training course provides palliative care nurses and selected clinical personnel the information necessary to safely prescribe morphine (126).

Palliative care modules should be integrated into undergraduate medical and nursing curricula that constitute the fundamental training of graduates from these programmes (116,124,127). There is also need for advanced degrees in medicine and nursing at the three campuses (in Jamaica, Barbados and Trinidad and Tobago) of the University of the West Indies, and education indicators and accreditation programmes need to be developed for health care providers (128). Additionally, there is an urgent need for the establishment of a national or Caribbean regional specialist training pathway for initial and ongoing training in palliative care for physicians, nurses and other health care providers (123).

8.6.1.2 *EDUCATION AND TRAINING: INFORMAL CARERS*

Family members were the main informal caregivers of persons with life-limiting or life-threatening conditions who were cared for and died at a private home (**Chapter 6**) and (**Chapter 7**). Unmet needs of patients and caregivers appear to be universal in part to the lack of social support but also to a lack of opportunities to gain the knowledge and skills necessary to provide care when the need arises (97,129,130). Particularly for the home setting, a grassroots (community lead) initiative to address this shortcoming can involve informal caregivers actively communicating about palliative and end-of-life care issues via social media, where they can organise support groups to develop their own palliative care skills. These community initiatives should be supported with resources from governmental and non-governmental sources (i.e., joint ventures) to facilitate standardisation of information and skills, e.g., physicians, nurses or grief counsellors can mentor caregivers during training sessions (1,131).

A Cochrane review on training volunteers for community-based palliative care programmes suggested that volunteers contribute positively to palliative care goals (132). The involvement of volunteers can extend the range of services, often beyond the opening hours of formal care provision, and they can operate within their own communities, work directly at the homes of patients and their families, or at a central community setting (133-135). Activities undertaken by volunteers can include practical patient care like nutrition and grooming (136) or transporting patients and their families to and from appointments (137), social support or companionship (138) or emotional support when taboo or difficult issues require discussion (139) including bereavement support for family members (140).

These or similar initiatives have been successfully implemented and continue to be in operation in resource-poor regions or developing countries like Kerala India (141) and Uganda where volunteers are also trained to give their clients medication or encourage them to take it (142). However, in the Caribbean volunteering may not be considered a cultural norm. However, it is possible that volunteering is dormant in our communities in Trinidad and Tobago. Apart from religious faiths that do organise volunteer groups for their different activities and projects, volunteers and volunteering are not obvious. In fact, a survey done by a volunteer organisation in Trinidad and Tobago in 2016 indicated that the post popular activities for their volunteers were mentorship and tutoring, raising awareness about social issues and participating in conservation of the environmental (143). The challenges reside not only in identifying possible volunteers to participate in palliative and end-of-life care activities in their communities, (activities they may be unfamiliar with), and how to sustain their interest and motivation to continue volunteering. But also, to convince clients (patients and their families) to open their doors to a large number of volunteers (139). These may be challenges of most volunteer groups or organisations, but it may be the case that sourcing the number of volunteers needed for community palliative care services may not be achievable in the short-term. A possible alternative would be to focus on family and friends, forming networks among them as they are likely to be already engaged with the concept of 'giving of their time' in the service of palliative care.

The physical, emotional and social wellbeing of caregiver's quality of life can be negatively affected (144,145), and they are susceptible to suffer symptoms of loneliness, anxiety and depression, diminished physical health, marital strain and restrictions of roles and activities (144,146). Government lead and supported formal training and support programmes for informal caregivers (family caregivers and volunteers) should be developed and implemented in each of the Regional Health Authorities. Apart from the knowledge, skills and camaraderie caregivers may gain from such programmes, they can also obtain coping skills, self-efficacy, confidence, social capital and various other outcomes that are beneficial for caregivers.

8.6.2 *RECOMMENDATIONS FOR POLICY*

The palliative care provision in Trinidad and Tobago is considered 'Isolated' (147), i.e., a national commitment to palliative care practice is absent and what exists lacks governmental scope and focused, social and financial support. At present there are no national policies that directly support palliative and end-of-life care issues or circumstances in Trinidad and Tobago. Information from our mortality follow-back study, (**Chapter 6**) and (**Chapter 7**), indicated that physicians do not feel supported in their practice in this respect, for example, the lack of a do not resuscitate (DNR) policy compels them to continue futile treatment, especially in institutional settings.

8.6.2.1 *NATIONAL PALLIATIVE CARE POLICY*

A national palliative care policy which can accommodate civil society and local government initiatives (148), should be developed and implemented. The World Health Organisation and other international advocates for palliative care have extensively recommended the need for national health policies in countries where palliative care is underdeveloped (149-156). Trinidad and Tobago and many other Caribbean nations are signatories to the 67th World Health Assembly (WHA) held in Switzerland in 2014 (157). Ministers of Health agreed to facilitate national action that will reduce barriers to the availability and access to palliative care (158).

The 67th World Health Assembly document highlighted key components that could be included in a national policy including: *(i) palliative care is fundamental to improving quality of life, well-being, comfort and human dignity for individuals; (ii) access to palliative care and to essential medicines including opioid analgesics for the relief of pain and suffering contributes to health and well-being; (iii) health systems have an ethical responsibility and health providers have an ethical duty to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care; and (iv) inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care* (157). The aim of a national policy would be to integrate palliative and end-of-life care into all national health plans and policies, e.g., cancer, non-communicable diseases, infectious diseases (HIV/AIDS and tuberculosis) and paediatrics, and to develop national palliative care standards (128).

8.6.2.2 *SCALE UP PALLIATIVR CARE SERVICES*

Current service provision needs to be scaled up and a public health model to palliative care should be adopted (97,128). Information from our place of death studies, (**Chapter 3**) and (**Chapter 4**), indicated that about thirty percent of deaths nationally occur at a private home. This suggests that there is great need for home care services, but these services must be coordinated to enable continuity of care. The capacity to expand palliative care services in communities exists. Excluding main government hospitals there are over 100 health centres and health facilities (an enhanced health centre offering additional services) that cater for the delivery of primary health care (159). A practical start could be to include palliative care as a function of primary health care at strategically (according to geography or population density) located health centres. This can be done in phases to form a national network over time. General practitioners are necessary in this initiative as our mortality follow-back study, (**Chapter 6**) and (**Chapter 7**), indicated that they are the main formal palliative care providers and they play a key role in care coverage. Additionally, a core multidisciplinary palliative care team in each of the five Regional Health Authorities can be established to provide support to general practitioners in the community.

8.6.2.3 *INVEST IN EDUCATION AND AWARENESS*

From our study, (**Chapter 7**), physicians with formal palliative care training did make different treatment and medical end-of-life decisions than those who had no such training. Also, information from, (**Chapter 6**), indicated that informal caregivers including family members were the main carers at the home setting, but their ability to provide appropriate care is unknown and it is likely that most have to training. Therefore, for a successful initiative it is essential that politicians, social activists, health care professionals and the general public are made aware about the current circumstances of dying from life-limiting and life-threatening conditions, but also about the benefits of palliative care to the patient, family members and care providers (148). For example, the World Health Organisation’s regional office can collaborate with the Ministry of Health to design public awareness campaigns to inform and educate the public, civil society organisations and health officials about palliative care, which can be delivered by different media platforms including, social, radio and television (128).

8.6.2.4 *INVEST IN PALLIATIVE CARE SERVICES WITH FUNDING*

Evidence has shown that health care costs can be reduced and the quality of patient and family outcomes improved by the early integration of palliative care services in managing patients with life-limiting or life-threatening conditions (160-165). For example, as recommended by the World Health Organisation, the Ministry of Health can oversee financing mechanisms necessary to develop palliative care services. This can include a finance subgroup comprised of palliative care providers, health economists, health system managers from each Regional Health Authority, and social service providers. Government should review existing funding and service delivery models to determine the cost of delivering palliative care at the different settings (128).

8.6.2.5 *UPDATE AND AMEND DANGEROUS DRUGS ACT*

The *“Dangerous Drugs Act”* in Trinidad and Tobago was last updated in 2007, this document’s purpose is to restrict the use of narcotic drugs and contains negative language pertaining to opioids such as *drugs, addiction* and *dangerous drugs*, but by extension the medical use of opioids for pain management is also restricted (166). Findings from our scoping review (**Chapter 2**), and our mortality follow-back study, (**Chapter 6**) and (**Chapter 7**), did indicate low use of and access to opioids for medical purposes as the medical opioid consumption in 2013 was 1–10 mg morphine equivalents/capita/year (167). To promote the increased use of medical opioid consumption, the World Health Organization’s roadmap for palliative care development suggests the formation of a government drug policy subgroup to review the medical use of opioids for pain management. Subgroup members should include, drug regulators, pharmacologists and pharmacists, law enforcement authorities, and if necessary national and international pain, and palliative care experts and may include representatives from the International Narcotics Control Board (INCB). The purpose here includes a review and as needed revision of the narcotic control laws and regulations that govern importation, registration, storage, distribution, dispensing, accountability, pricing, and prescribing practices to ensure the adequate availability, accessibility, and affordability of essential palliative care medicines including oral morphine (128).

8.6.2.6 *INVEST IN QUALITY OF DEATH CERTIFICATION AND DEATH CERTIFICATE DATA*

Death certificates can be a useful research tool (17,32,45,49). Data from our studies, (**Chapter 3**), (**Chapter 4**), (**Chapter 6**), and (**Chapter 7**), remarked on some deficits of the death certificate form used to register a death. We observed inconsistency in quality of completion and absence of some necessary information that limits its use as a useful source of routine data in monitoring quality end-of-life care. For example, there are inaccuracies in the certification and coding of some underlying diseases (32), and important sociodemographic information like age, sex and race/ethnicity of the decedent were missing (46).

Other sociodemographic information that is currently not on death certificates but might be useful to record and monitor include, marital status, income bracket, education level, living arrangement and level of urbanisation of the usual place of residence of the deceased. This information is considered reliable predictors for the place of death (32,45,168), and modifications should be made to add these variables to death certificates. Additional information such as nationality (country of birth), or residence characteristics like municipality of death and municipality of residence, or health care system characteristics such as the number of hospital beds per 1,000 inhabitants may also be useful to include (32).
On death certificates place of death is restricted to four categories, and groups together very diverse places, i.e., nursing homes, private hospitals, hospices and geriatric homes, which can hinder the evaluation of end-of-life care policies that uses death certificates as a data source. Therefore, separate place of death categories should be made available including the location of death at a hospital, e.g., the palliative care unit, or at a hospice or whether the place of death was at a prison (32).

Some important information about a patient's characteristics or environment are absent from death certificate data. This can obstruct its usefulness for scientific research unless data can be linked to other datasets that can give information about the person's dying circumstances (32,49). For example, information about the person's preferred place of death (private home or hospital), or information about the characteristics of the disease trajectory and predictability of death, or hospitalisation and individual health care use (32). Privacy issues must be protected but to move beyond an administrative data collection source to a source for research where quality of dying can be evaluated there should be opportunity to link these types of data to death certificate data (49).

Relevant government bodies and medical schools should invest in the quality of death certification by developing tools or increasing the skills of physicians and striving for accuracy and uniformity (169). Also, a certifying physician cannot be expected to know every detail about a patient nor is it appropriate to burden bereaved family members for information about their deceased relative (32). Therefore, investing in an electronic health records system capable of linking to population census or death certificate data may be a worthwhile endeavour. Elements of a national information and communication system are being organised by the government of Trinidad and Tobago in an Information and Communication Technology plan 2018-2022 (170) and a Health Information Management System is mentioned in the country’s 2030 national strategic plan (171). This suggests that policy makers consider digital information an important priority and are willing to provide resources to develop such a system.

8.6.3 *RECOMMENDATIONS FOR RESEARCH*

Education, policy and drug availability are essential components of the World Health Organization’s public health approach to palliative care implementation (172). As an emerging discipline with increasing coverage, a palliative care development strategy must be guided by local evidence (173). Research on end-of-life care in Trinidad and Tobago, the Caribbean and other low-resourced and developing countries is lacking. Information from such countries about the circumstances of dying from life-limiting and life-threatening conditions are not represented globally (20). Considering the lack of a research infrastructure a recommendation can be to first use available secondary data, including death certificate and other administrative information, to do robust research like place of death studies, this can be followed by an assessment of the financial cost of providing palliative care.

8.6.3.1 *PLACE OF DEATH*

With the most recent mortality data available, we suggest further population-level place of death studies be done in resource-poor countries, including trends in the place of death in relation to palliative and end-of-life care that consider shifts in the underlying cause of death, age and sex of the deceased populations. Qualitative studies can be considered to allow a better understanding of what influences choices about place of death, including care services, social resource change, attitudes, beliefs and preferences.

The preferred place of death or place of care are unknown and an understanding of such a preference would be beneficial to policy makers and government officials in order to allocate necessary resources and services. In Trinidad and Tobago, a majority of deaths indicative of a palliative care need occurred at a government hospital, (**Chapter 3**) and (**Chapter 4**), both quantitative and qualitative studies should be done to evaluate and understand the quality of care received (by patients) and delivered (by health care providers) at this setting.

Given the importance of informal palliative care indicated by our findings, (**Chapter 6**), future studies also need to focus on caregiver needs and experiences, particularly at the private home setting. Longitudinal studies that cover more than the time period immediately before death could also be considered.

8.6.3.2 *COST IMPLICATIONS OF PROVIDING PALLIATIVE AND END-OF-LIFE CARE*

With the current trend of an aging population and prevalent chronic disease, the need for palliative care services at different settings should be assessed. Current services should be systematically evaluated to get a better understanding of the costs (e.g., economic, and human resource) of providing palliative care, and the out-of-pocket costs to those that use the services. Concurrently, an evaluation of the care provided at government hospitals (that can be recognised as palliative and end-of-life care) should be done. Data can be reconciled to better understand where the demands for resources are to efficiently build and allocate needed services.

8.6.3.3 *INTERVENTION STUDIES*

Interventions that target some of the specific needs surrounding palliative and end-of-life care in Trinidad and Tobago are needed, e.g., family and caregiver training and support programmes, and death education programmes for the general public. This requires two types of research. Firstly, robust public health (health promotion) research focusing on the development of new or adapted interventions, applying the necessary implementation science perspective and involving the various relevant stakeholders including; communities and neighbourhoods, civil society organisations, health and allied health care providers and government agencies (174). Secondly, research that applies experimental designs that will allow drawing conclusions about causality of interventions and their mechanisms of action on relevant outcomes. This type of research would be a major step for moving towards a more evidence-based end-of-life care programme and planning.

8.6.3.4 *PALLATIVE CARE FOR CHILDREN*

Care for adolescents and children is included in the World Health Organisation's definition of palliative care (149), but the dearth of studies done on the availability of, access to or care needs of this demographic in any Caribbean nation is startling. Such studies must be included in a national health research agenda.

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8.7 SUMMARY

1. BACKGROUND

Worldwide, the need for palliative care is great and is increasing due to the burden of ageing of the world's population and increasing incidence of chronic and degenerative medical conditions. In high income developed countries substantial progress has been made in the development of palliative and end-of-life care. Supported by robust population level research considerable investment has been made to ensure quality end of life outcomes. Research on the social and clinical circumstances of dying, for example, has brought to the fore important topics such as: access to palliative care, choice in the place of care and death – private homes, care homes or hospices – or the development of appropriate laws and policies that address ethical issues such as withholding or withdrawing care and even medical aid in dying. Furthermore, palliative care is considered best practice in alleviating the relief of suffering at the end of life and is an important indicator of quality care when it is implemented early in the trajectory of a life limiting condition.

Outside of Western Europe, the United Kingdom, North America and Australia, the majority of people needing but not receiving effective palliative care or even access to care live in developing and resource-poor regions or countries. *Resource-poor relates to the limited capability to provide care for life-threatening illness due to a lack of necessary human and material resources and consequent services, inadequate education and training for health care providers, and a lack of governmental policies to support the provision of palliative care.* Only about 14% of people worldwide who need palliative care currently receive it. For children, 98% of those needing palliative care live in low- and middle-income countries with Africa contributing approximately half of this need. In resource-poor settings, for example, a major public health challenge is to ensure that minimum standards are available to offer pain relief or other symptom control, psychosocial, emotional and spiritual support. In countries with a poor health infrastructure but a tradition of strong family support, home-based access to care can be a way of achieving quality care and coverage. Understandably, resources available to allocate to palliative care in low- and middle-income countries vary and important traditions and cultural sensitivities towards health, terminal illness, dying and death must be considered when a palliative care programme is implemented. In a majority of low-resourced and developing countries, complex factors including the lack of a research culture and infrastructure and lack of incentives for research activities has relegated health research as a luxury, which is often funded by external sources. A major obstacle and continuing challenge to the further development of palliative care in developing countries is a lack of information surrounding the circumstances of dying from chronic and degenerative medical conditions, which limits in-depth exploration of how such countries are providing care. Consequently, dying from a terminal illness and the related experiences encountered at the end of life by patients, their family and caregivers in these countries are largely unexplored through systematic research.

THE ENGLISH-SPEAKING CARIBBEAN

English-speaking Caribbean nations are twelve territories with comparable colonial experiences (former British) where English is the official language, they include: Antigua and Barbuda, The Bahamas, Belize, Barbados, Dominica, Grenada, Guyana, Jamaica, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines and Trinidad and Tobago. These nations are connected culturally and socially, share similar political and educational structures and socioeconomic links such as the Caribbean Community and Common Market, and are classified by the World Bank as upper-middle to high income developing countries. Mostly Island nations, they are members of the United Nations Conference of Small Island Developing States (SIDS) that are a group of developing countries susceptible to vulnerabilities, for example: their geographic position can be remote with limited access by international travel connections and exposure to natural hazards like hurricanes; small populations dependent on a narrow range of exports, limited access to affordable international finance that can restrict economic activity, and they are extremely vulnerable to exogenous shock. They also have similar health structures based on a model that consists of a centralized ministry of health and peripheral health facilities. Health services delivery is through a mixture of public and private providers where government health services are mainly free at the point of delivery. Since 2013, the Caribbean Public Health Agency (CARPHA) is the single common regional public health authority, and a Caribbean palliative care association was formed in 2019.

The World Bank's classification of these countries as upper-middle to high income is primarily based on the calculation of 'gross domestic product (GDP)', an indicator of well-being and development that is exclusively based on material wealth and used to classify a society's standard of living and to compare wealth among countries. However, GDP per capita may not be the best index to measure standard of living within a country as economic inequalities (poor-rich divide) are not represented nor are non-material societal values like leisure, environmental quality or levels of health and education.

The Caribbean has a long migratory history with estimates for the Caribbean population living abroad reaching 22%. The largest number of immigrants from the English-speaking Caribbean living in the United States are from Jamaica, Guyana, and Trinidad and Tobago. Possibly a consequence of decolonialisation, Caribbean migrants have been leaving their home countries – mainly immigrating to North America and the United Kingdom – motivated by pursuing higher education or prospects of economic stability in the form of employment or better paying employment with better working conditions, but also in search of better and more secure environments with political and social (e.g., less violent crime) stability and a relatively higher standard of living. However, an implication of emigration is the 'brain drain' caused, as migrants are often young and educated, many of whom are health workers, especially nurses followed by physicians, but includes engineers and other skilled professionals.

SOCIODEMOGRAPHIC CHANGES

Important epidemiologic and social developments have brought about changes to the population of the Caribbean. Improvements in medical technologies and treatments, and advancements in public health and access to health care have resulted in an increased life expectancy. In Latin America and the Caribbean life expectancy is projected to increase to 80.7 years for women and 74.9 years for men between 2025 and 2030. In 2017, 13% of the population were aged 60 years and older, and by 2030 this demographic is expected to account for more than 17% of the total population in this region. It is anticipated that the aging population trend will be associated with a decrease in fertility, which can lead to drastic changes in the aging index (i.e., the ratio of older people to people under the age of 15), which could reach 142 older persons for every 100 children by 2040. The leading causes of death have also shifted from communicable diseases, for example, malaria and tuberculosis to non-communicable diseases (NCDs) like cardiovascular diseases and malignancies. The reality is that non-communicable diseases are now the leading cause of premature deaths, representing nearly 50% of all deaths of persons under 70 years of age, however, of the Americas the Caribbean region is the most worst affected by non-communicable diseases.

These developments increase the possibility that a growing number of persons will suffer and eventually die from chronic conditions, deaths likely preceded by prolonged periods of illness requiring and would greatly benefit by palliative care. However, a number of broad and significant barriers restrict access to palliative care including: the lack of national health policies and systems that include palliative care as a health priority, the absence of awareness of palliative care among health professionals and limited training of physicians in palliative medicine; overly restrictive regulations of opioid pain management (opioid analgesics are essential for treating serious health-related suffering associated with many advanced progressive conditions including those of non-communicable diseases); opiophobia or the fear, prejudice and misinformation about the appropriate use of opioids for medical use; and the curative focus in medicine on extending life while caregiving and quality of life near death is neglected.

PALLIATIVE CARE AND PAIN RELIEF

Core components of universal health coverage are palliative care and pain relief, which are considered to be key elements of quality health care, but the need for palliative care and pain relief has been largely ignored. Of the 56·2 million deaths recorded worldwide in 2015, 45% experienced serious health-related suffering and possibly died with undertreated pain, 80% of those were from developing regions where palliative care and pain relief is scarce or non-existent. Less than 15% of the world's population lives in a high-income country, but they consume more than 90% of opioid analgesics. For example, the annual distribution of morphine is more than 68,000 mg per patient in need of palliative care in Canada and 55,000 mg per patient in the United States of America but only 5 mg per patient in need of palliative care in Haiti. Indeed, in many developing countries and resource-poor regions of the world, access to medical opioid analgesics is either lacking or absent. The International Narcotics Control Board (INCB) reported that although the overall trend in the Caribbean indicates an increased use of opioids for medical purposes from 2001–2013, there were considerable variations among countries and consumption remained below an adequate level.

Studies done on Caribbean populations concluded that the need for palliative care services is driven by demand from an aging population and increasing morbidity from chronic diseases, cancer and HIV/AIDS as well as the need for health care policy, training of staff, education, and access to effective analgesia. These are commonalities that could allow for some generalisation that the case of one Caribbean country (Trinidad and Tobago) – i.e., investigation of the circumstances of dying from illnesses indicative of a palliative care need – may be applicable in other Caribbean countries.

TRINIDAD AND TOBAGO

In 2019 the population was estimated at 1.4 million of which 18.2% was 60 years and older, by 2030 the population is anticipated to increase slightly to 1.41 million and then decrease to 1.34 million by 2050. However, persons 60 years and older are anticipated to steadily increase to 24.5% by 2030 and 36.5% by 2050. Of Caribbean countries Trinidad and Tobago (T&T) has one of the highest rates for morbidity and mortality from non-communicable or chronic diseases, which were estimated to have accounted for 81% of all deaths in 2016. Cardiovascular diseases 33%, cancers 15%, diabetes mellitus 15% and chronic respiratory diseases 3% were among the main causes of death, all medical conditions indicative of palliative care needs. Palliative care in T&T was reported as ‘Isolated Palliative Care Provision’ where there is an absence of a national commitment to palliative care practice, and existing services are limited and lacking in governmental, social and financial support, for example, unreliable availability of morphine at the nation’s health institutions and a small number of hospice and palliative care services in relation to population size; included in this category was Jamaica. Available service provision includes: in Trinidad there is a nurse led home-based oncology/palliative care service in the eastern (RHA), a government operated palliative care unit (comprised of a 12-bed out-patient service and hospital consult) in the north-central (RHA), two 12-bed non-governmental hospices in the north-west (RHA), and in the Tobago

(RHA) a nurse-led home-based palliative care service. However, a hospital-based outpatient palliative care clinic in the Trinidad south-west (RHA) was suspended in 2019 citing lack of human resource. Efforts to revive it in 2020 were abandoned due to shifting priorities of the Regional Health Authority relating to the emergence of the Coronavirus disease 2019 (COVID-19). A national palliative care association began operating in 2011.

In addition to the lack of clinical infrastructure, there is also a lack of general research infrastructure to support innovation and policy in this domain. Numerous obstacles and challenges of doing research in developing countries exists, and a common theme of '*a lack of information and lack of original studies*' on, for example, palliative care in the Caribbean persists. Because there is a lack of data from any Caribbean country through large-scale robust studies conducted to confirm the circumstances of dying and the provision of palliative care, I undertook this research project as I wanted to better understand and offer more insight in the field but importantly to generate data, knowledge and evidence, around palliative and end-of-life care from a Caribbean context.

2. STUDY OBJECTIVES AND RESEARCH QUESTIONS

The main objectives of this dissertation are to describe the circumstances under which persons die and to describe the medical care and treatment a person received prior to their death in Trinidad and Tobago.

I. The first aim is to identify and comprehensively review the knowledge and knowledge gaps documented in the literature on palliative and end-of-life care in the English-speaking Caribbean region. The following research questions will be answered:
   1. What are the common themes documented in the literature on palliative and end-of-life care in the English-speaking Caribbean? What are the barriers and suggested improvement strategies to further develop palliative care in English-speaking Caribbean nations?

II. To compensate for the lack of research data, the second aim is to explore and use available routinely collected population-level administrative data on dying in Trinidad and Tobago. The following research questions will be answered:

1. Where do people die in Trinidad and Tobago? What are the social circumstances and characteristics associated with their place of death?
2. What is the trend in the place of death, and what are the implications for end-of-life care and policy practice related to trends?

III. The third aim is to generate reliable and representative data and insight regarding end-of-life care and medical end-of-life decisions of non-sudden deaths in Trinidad and Tobago, and identify and describe important differences in end-of-life care and decision making between sociodemographic and clinical groups. The following research questions will be answered:

1. Is it feasible to conduct a representative national survey by adapting a questionnaire on palliative and end-of-life care to the socio-legal context of Trinidad and Tobago?
2. What are the characteristics of palliative and end-of-life care and treatment and medical decision making at the end of life in Trinidad and Tobago?
3. What are the characteristics of caregivers providing palliative and end-of-life care for persons dying at home in Trinidad and Tobago?
4. What is the sociodemographic and clinical profile of patients who receive palliative and end-of-life care at home in Trinidad and Tobago? What are the characteristics and incidence of different types of medical end-of-life decisions made at the end of life for persons dying at home?
5. Is there a difference in medical end of life decision-making in Trinidad and Tobago depending on the physicians' formal palliative care training?

3. METHODS

SCOPING LITERATURE REVIEW (RESEARCH AIM I.1)

A systematic scoping review was done because we wanted to broadly explore the subject of palliative and end-of-life care in English-speaking Caribbean nations. Methodological details can be found in (Chapter 2).

POPULATION-LEVEL ANALYSIS OF ROUTINELY COLLECTED ADMINISTRATIVE AND SUPPLEMENTARY HEALTH DATA (RESEARCH AIMS II.1-2)

We conducted population-level analyses of routinely collected death certificate and supplementary health data.

I. PLACE OF DEATH IN 2010. At the time the study was done, 2017, the most recent available year of completed mortality data was 2010 (N=10,221). The national death registry the Central Statistical Office (CSO) also provided supplementary census data (community classification of urbanisation), and data on percent of the population living in an urban setting in 2010. The Ministry of Health provided health resource data, i.e., the number of government hospital beds (n=2009) and the proportion of beds per Regional Health Authority (RHA): North-West, North-Central, South-West, Eastern and Tobago.

II. PLACE OF DEATH TREND ANALYSIS 1999 – 2010. The study was done in 2018 and due to coding delays, fully completed and reliable datasets were only available for the years 1999 through 2010. Demographic characteristics of decedents (N=118,703), including the year, age, gender and main underlying cause of death, were extracted from the records. A subcategory of persons who died from some of the most common chronic life-limiting conditions that are indicative of a palliative care need was considered.

POPULATION-BASED MORTALITY FOLLOW-BACK STUDY BASED ON DEATH CERTIFICATES (RESEARCH AIMS III.1-5)

In 2018 a population-level mortality follow-back study based on a representative sample of death certificates of home deaths was done. The sampling framework was obtained from death certificates that were sampled at the CSO. A mortality follow-back approach was used as it is an efficient means to collect robust population-based information on the last days or months of life. Ethics approval for this study was granted by the Ministry of Health of Trinidad and Tobago (no file number available: The Ministry does not catalogue approvals issued for research). The Trinidad and Tobago Medical Association was a neutral consultant and partner in the planning and conduct of this study. Three reports were written to this effect.

I. QUESTIONNAIRE DEVELOPMENT. A questionnaire was developed, (Chapter 5) and cognitively tested to collect population-based information in a standardised manner on the medical characteristics of palliative and end-of-life care, (i.e., care provided in the last 30-days before death), and the circumstances of dying. Modelled on a questionnaire originally developed in the Netherlands in 1990, which was successively used in slightly adapted versions in other countries between 1997 and 2016, our questionnaire was adapted by cognitive testing and face validation to ascertain it was suitable and relevant to the context of Trinidad and Tobago. The questionnaire was used in the mortality follow-back study that yielded two reports.

II. PALLIATIVE AND END-OF-LIFE CARE, (Chapter 6) and the other on MEDICAL END-OF-LIFE DECISIONS, (Chapter 7). A random sample of Trinidad and Tobago residents aged 18 years or older, who died at a private home between March 1 and August 31, 2018, was drawn from the death certificates at the CSO; the sampling fraction was 1 in 2. The general practitioner certifying each death in the sample was invited by postal mail to complete a questionnaire about the end-of-life care in the specific case. In total 752 deaths were sampled. The neutral third party, was involved in the mailing procedure as an intermediary between responding general practitioners, researchers, and the CSO to maintain general practitioner anonymity and guarantee that completed questionnaires could never be linked to a particular patient or physician.

4. KEY FINDINGS

PART I – IDENTIFYING KNOWLEDGE AND KNOWLEDGE GAPS IN THE LITERATURE

REVIEW OF THE LITERATURE

We performed a scoping review, (Chapter 2), in order to describe the state of knowledge as described in the published academic and grey literature on palliative and end-of-life care in English-speaking Caribbean nations, a group of resource-poor countries that share similar cultural and historical backgrounds, including similar economic, environmental and research challenges. A systematic search identified only twenty-five published articles that spanned the years 1991 to 2015, ten of which were original studies, reflecting the scarcity of (empirical) information that could be used to inform and guide public health practice regarding palliative and end-of-life care. We identified five important themes in the literature:

1) socioeconomic and cultural norms about terminal illness and death that influence the development and delivery of palliative and end-of-life care; 2) limited access to opioids for medical use; 3) limited palliative care services as compared to need; 4) unmet needs for palliative care; and 5) a lack of relevant research activity in the region. Some common barriers to the development of palliative care in the English-speaking Caribbean include: inadequate health care systems that deny universal health coverage and that offer few options regarding palliative care support services to patients with life-limiting or life-threatening conditions; an absence of documented policy and outdated beliefs on the effective use of opioid analgesics; limited awareness of and access to available palliative care services fosters unmet needs; poor communication between health care providers, patients and their family hinders accurate information sharing; cultural taboos and attitudes of the public toward terminal illness and death are strongly influenced by religious beliefs; and the absence of a research culture.

Compared to other developing countries in Latin America or Africa our findings were not unique since the lack of empirical information on the provision of and access to palliative care are common challenges in resource-poor countries and regions. However, our study identified opportunities for improvement in the English-speaking Caribbean for the overlapping issues of practice, policy, and research and offers a conceptual framework for further research.

PART II – USING AVAILABLE ADMINISTRATIVE AND ROUTINELY COLLECTED DATA TO DO POPULATION-LEVEL STUDIES IN RESOURCE-POOR CONTEXTS

WHERE DO PEOPLE DIE IN TRINIDAD AND TOBAGO

In (Chapter 3) we analysed routinely collected death certificate data in Trinidad and Tobago. We obtained a dataset for the year 2010 from the national death registry. 2010 was the most recent available year at the time of the study. Supplementary health data was obtained from the Ministry of Health and included in our analyses. The largest proportion of deaths (55.4%) occurred in government hospitals; whilst (29.7%) occurred at a private home and (5.9%) in a nursing home or non-government (private) hospital. We observed that the place of death is influenced by age, underlying cause of death, sex, level of urbanisation and race/ethnicity. Death at home becomes more likely with increasing age. Compared with the reference group those aged 18–69 it is more likely at ages 70–89 (OR 1.91, 95% CI 1.73 to 2.10) and age 90–highest (OR 3.63, 95% CI 3.08 to 4.27) to die at home. Home death was also more likely for those with diseases of the nervous system (OR 1.44, 95% CI 1.08 to 1.93) compared with the reference group, people dying from cardiovascular diseases, but less likely for people with cancer (OR 0.85, 95% CI 0.74 to 0.97), cerebrovascular disease (OR 0.61, 95% CI 0.51 to 0.72) or respiratory diseases (OR 0.74, 95% CI 0.59 to 0.91) than the reference group. We also observed that dying from diseases of the nervous system (OR 0.49, 95% CI 0.37 to 0.66) was associated with a lower chance of dying in a government hospital.

Compared to women men have a higher likelihood of dying at a government hospital (OR 0.87, 95% CI 0.80 to 0.94), and living in a rural area was associated with a higher likelihood of dying at home (OR 1.51, 95% CI 1.35 to 1.70) and a lower likelihood of dying in government hospital (OR 0.77, 95% CI 0.69 to 0.86). Our reporting of the different ethnic groups is according to how this demographic is collected on death certificates. There appears to be inequality between ethnic groups regarding place of care and death since the place of death of people categorised as ethnically white is different from every other race/ethnic group as 48.8% died at home and 17.1% in a nursing home or private hospital, which was more than any other ethnic group, whereas 29.3% died at a government hospital, the least of any other group. A regression model with the variable race/ethnicity (61.1% of data were missing) as an independent variable, controlling for age, sex and cause of death, confirmed a significantly lower chance of dying at home for black (OR 0.51, 95% CI 0.27 to 0.98) than for ethnically white people and a larger chance of dying in hospital for East Indian (OR 2.32, 95% CI 1.14 to 4.71) and black (OR 3.33, 95% CI 1.64 to 6.74) compared with ethnically white people.

This study demonstrates that even in low-resourced environments, it may be possible to use death certificate and supplementary health data to study the place of death and variation in it according to sociodemographic and clinical characteristics. The findings suggest that attention is required in different care settings to monitor the availability, affordability and access to good end-of-life care but also for guaranteeing equity (e.g., by ethnic groups and clinical presentation) in these factors.

THE PLACE OF DEATH OVER TIME

In, (Chapter 4), we further explored the secular trends in the place where people die since this can have important consequences for health care costs, including in small resource-poor countries, as end-of-life care in hospitals has been demonstrated to be more expensive than out-of-hospital care. Fully completed and reliable datasets were available for the years 1999 through 2010 where the total number of observed deaths were (N = 118,703). The three main recorded causes of death over this period, ranked according to frequency, were cardiovascular diseases, diabetes mellitus and malignancies. A subcategory of persons who died from some of the most common life-limiting conditions was considered. These included the following diseases and their corresponding International Classification of Diseases 10 (ICD10) coding: cardiovascular disease (I00–I52, I70–I99), cancer (C00–C97), respiratory disease (J00–J99), diseases of the nervous system (G00–G99), cerebrovascular disease (I60–I69) and diabetes mellitus (E08–E13).

The proportion of deaths from cancer increased in the period 1999-2010 and deaths from cardiovascular diseases decreased over time. We observed that the proportion of deaths in government hospitals sharply increased, from 48.9% in 1999 to 55.4% in 2010. However, the proportion of deaths in private homes strongly decreased from 38.7% to 29.7% in the same period. Over time, shifts in hospital and home deaths were even more striking for deaths that occurred from conditions that, according to operationalizations found in the literature, are indicative of palliative care need. Deaths from cancer were most noticeable where home deaths fell from 51.6% in 1999 to 31.2% in 2010 but hospital deaths increased from 38.4% to 54.7% during the same period. The proportion of deaths occurring in a nursing home or private hospital decreased (7.1% to 5.9%), and deaths occurring in other places, inclusive of private geriatric homes, increased (5.3% to 8.9%). We compared observed and standardised (for age and sex) figures for the period 1999 to 2010 but observed little variation.

This study showed a strong ‘hospitalization of death’ trend, similar to the trends observed in many developed and high-resource countries in the second half of the 20th century. However, a reversal trend over the last two decades was observed where in many of those countries fewer in-hospital deaths occurred, and this has been related to palliative or end-of-life care strategies. Hence, the continuing trends in Trinidad and Tobago suggest a need for a national strategy on palliative and end-of-life care that acknowledges both the increasing number of people seeking care at government hospitals and that considers alternatives to accommodate out-of-hospital care and deaths.

PART III – GENERATING NEW DATA AND INVESTIGATING THE CIRCUMSTANCES OF END-OF LIFE CARE AND DYING FROM SERIOUS ILLNESSES USING A MORTALITY FOLLOW BACK STUDY

QUESTIONNAIRE DEVELOPMENT FOR MORTALITY FOLLOW-BACK STUDIES

The empirical material for this study, (Chapter 5), mainly draws upon interviews that were carried out with 18 physicians with varying backgrounds including, general practitioners, oncologists, gerontologists, internal and palliative medicine clinicians. Fourteen physicians from Trinidad and four from Tobago, voluntarily participated in face-to-face interviews where we obtained face and content validity of the questionnaire. Some important changes to the initially proposed questionnaire included: the addition of a palliative care definition and instructions for completion; adjustments to question formulations, wording, sequence of questions, answer options and layout; and removal or addition of questions and answer options.

Our study demonstrates that despite challenges in doing public health related research in a resource-poor or developing country context, it is possible to use existing instruments from resource-rich countries. However, it is clearly important to make relevant sociocultural and clinical adaptations to the specific context.

PALLIATIVE AND END-OF-LIFE CARE FOR PATIENTS DYING NON-SUDDENLY IN THE HOME SETTING

(Chapter 6), describes the findings from this study regarding the palliative and end-of-life care that patients with an end-of-life trajectory received prior to their death at home. Three hundred and nine questionnaires representing 21% of recorded adult deaths that occurred at a private home and their death certificates available during the study period were mailed. The survey response rate was 31% (N = 96). Of these, 76% were non-sudden deaths but

(27.4%) of people who died non-suddenly from conditions indicative of a palliative care need did not receive any palliative care. There were no significant differences for sex (P = 0.12), age (P = 0.62), or cause of death (P = 0.85) between the decedents in the response sample compared to all deaths surveyed.

Overall, the patient's family members and general practitioner were the most involved caregivers. Family members provided palliative care in (60.3%) of the cases and exclusively in 22 (30%) cases. General practitioners were involved in care in (39.7%) of cases. Family members and general practitioners provide a large part of the care and play important roles for their dying relatives and patients regardless of the disease. Specialised palliative care services are not often used as only (6.8%) of patients received it prior to their deaths. In the last 30-days of life, however, apart from general practitioners, the caregivers most often involved in care were family members (89.0%), nurses (31.5%), and medical specialists (15.1%). Also, in the last 30-days of life, the most prevalent treatments included analgesics (53.4%), antibiotics (34.2%), and artificial hydration (26%).

Our examination of the differences in care and treatment between noncancer and cancer deaths found that in cancer cases, decedents received it mainly from family members (73.3%) followed by general practitioners (60%) and specialised palliative care services (13.3%). A greater proportion of deaths from cancer received analgesics (93.3%) than noncancer (43.9%) deaths, (P = 0.003). General practitioners prioritised comfort maximization (60.3%) as the main goal of care in the last week of life, and analgesics (53.4%) were the predominant treatment for achieving this goal.

Our study shows that informal caregivers, particularly family members, are most important in delivering palliative care to their terminally ill relatives in the community. Therefore, programmes to train family members to provide necessary end-of-life care are critically important particularly for resource-poor countries that lack trained professionals.

MEDICAL END-OF-LIFE DECISION-MAKING IN NON-SUDDEN HOME DEATHS

Our data, (Chapter 7), shows that most general practitioners (69.8%) had no formal palliative care training, i.e., either as part of their medical education or postgraduate education programme. Most considered that their expertise in end-of-life communication with their patients (78.1%) and patients' family members (84.4%) was self-taught and developed through experience over the years. Also, most general practitioners (61.6%) did not have any discussions with their patients on end-of-life treatment options but the patient's partner or relatives were included in discussions in most cases (75.3%). However, when discussions included patients, the most common were about giving medications to alleviate pain and symptoms (30.1%), withholding treatments (13.7%) or withdrawing treatments (4.1%). When general practitioners with formal training were compared to those without, we found that discussions with patients about withholding treatments (25% compared to 6.7%) and about giving medications to alleviate pain or symptoms were more likely to occur. Those without formal training more often tended not to discuss any treatment options (75.6% vs 39.3%, p = 0.002).

The most prevalent medical end-of-life decisions were the administration of morphine or other opioid (20.5%) and withholding artificial hydration and nutrition (6.8%). Of the non-treatment decisions, no treatments were withdrawn but life-prolonging treatments were withheld in 7 (9.6%) deaths. The most common withheld treatments were artificial hydration and artificial nutrition 6.8% followed by artificial ventilation and cardio-pulmonary resuscitation 4.1%. In 34.2% of cases no medications were used to alleviate patient symptoms in the last seven-days of life, but Morphine or other opioids 20.5% and Diazepam or other benzodiazepines 17.8% were the most common medications given during this time. We found that general practitioners who had formal training in palliative care, either as part of their medical degree or through a postgraduate programme, were more likely to prescribe or administer opioids in the last seven-days of life 35.7% than those who had no formal training 11.1% (p = 0.01).

Our study shows that relatively few general practitioners have any formal palliative care training, but findings suggest an association between training in palliative care and the likelihood of treating patients with opioids at the end of life and discussing end-of-life treatment options with the patient and other caregivers.

5. DISCUSSION OF MAIN FINDINGS

LIMITED PALLIATIVE CARE SERVICES

Limited palliative and end-of-life care services in Trinidad and Tobago is a common theme across our studies and appears to be a shared challenge with other Caribbean countries. Central to this challenge is the increasing need for appropriate health care services to address the prevalence of people living with serious life-threatening or life-limiting illnesses. Coupled with aging populations suffering with a range of chronic comorbid conditions, dying from serious illnesses can become a burden on a country's health system. This scenario can affect high-income developed countries as well as developing and resource-poor countries. There are few options for formal palliative care delivery. In relation to the number of people with chronic medical conditions we can conclude that the current service provision falls short.

SETTINGS OF END-OF-LIFE CARE

High prevalence rates for life-limiting and life-threatening conditions including, cardiovascular diseases 33%, cancers 15%, diabetes mellitus 15% and chronic respiratory diseases 3% were among the main causes of serious health related suffering and death, and all are medical conditions indicative of palliative care need. The range of care will vary according to the need, but it appears the health care system will increasingly be challenged to provide palliative care across different institutions and settings in the foreseeable future.

It appears that resources are concentrated in government hospital settings and little attention and resources are focused elsewhere. Across all settings, the financial costs of care at the end of life can be substantial, but hospital care, particularly acute care, has been demonstrated to be more expensive than out-of-hospital care. Services and care at geriatric homes or assisted living facilities are unexplored at this time but our place of death trend study, (Chapter 7), indicated that the number of deaths at this setting is increasing. This scenario illustrates the need for widely accessible palliative care services that are integrated into the health care system according to an appropriate model, for example, a palliative care unit at each main government hospital, or care in the community which will include home care, or a combination of both. Nevertheless, urgent attention from policy makers and government health care decision-makers is needed.

ROLE OF INFORMAL CARE

A majority of deaths, in Trinidad and Tobago, were at a government hospital but the prevalence and type of palliative care received by those who needed it is unknown. In other words, government hospitals may not be the preferred place to receive palliative and end-of-life care. But due to a lack of options, the perception by those needing care may be that government hospitals are the only settings that can provide the level of care that is expected. Although our findings were calculated on data dated 2010 and before, we might assume that a significant number of deaths do still occur in a private home. With the few and limited services available the challenge of how to provide palliative and end-of-life care to those needing it in the home setting remains an irresolute issue.

Of all deaths worldwide it is estimated that palliative care could be beneficial for up to 74% of those who had a life-limiting or life-threatening condition, but where existing formal palliative care services are falling short, there is opportunity for care provided by informal caregivers. By informal caregiver we mean someone who provides or arranges unpaid assistance to a loved one, relative, friend or stranger (volunteer) because illness or disability rendered them incapable of selfcare. Informal caregivers, particularly family members, of persons with life-limiting or life-threatening conditions are important contributors of care. Their involvement can improve the overall quality of life of their loved ones by enabling activities of daily living such as; eating, hygiene and grooming or by offering emotional support. Their important role as front-line carers is evident as they are the ones giving medications (once trained to do so), e.g., for pain, and monitoring its effectiveness by observing for signs of undertreatment, or are acting as care coordinator and communicator between the patient and health care providers about the patient’s condition. Additionally, palliative home care appears to positively impact quality outcomes for patients including reduced symptom burden, improved care quality and reduced end-of-life health care costs.

In developing and resource-poor countries that have underdeveloped palliative care services and where the safety net of a responsive social welfare system may not be available, viable and alternative solutions of advancing palliative care must be explored. The grassroots public health approach to palliative care in the Indian state of Kerala, which utilises models of community participation, and where services are community-funded and supported in part by volunteerism may be an appropriate model to replicate. However, the need for and role of formal palliative and end-of-life care services should not be substituted. Therefore, a public health model, one that incorporates components of specialist and generalist palliative care services together with communities and neighbourhoods and civic palliative care programmes can be considered. To some degree elements of these components may already exist in communities in Trinidad and Tobago, and it is through the community structures that national health services have a responsibility to facilitate community empowerment and fulfil the functions of a public health model to palliative and end-of-life care.

DOING HEALTH RESEARCH IN THE CARIBBEAN

An understanding of the bureaucratic societal and organisational culture can help the researcher navigate the challenging and hurdle-filled process of doing health research in this region. The cultural *modus operandi* of how things are done is likely linked to the Caribbean’s colonial legacy. I am hopeful that my experiences and suggestions may encourage further public health and palliative care research. As a national of Trinidad and Tobago I can say with some confidence that the societal and organisational culture of this small country is conservative, formal and pyramidal or top-down. This is by no means a judgment but merely an observation that can affect the undertaking of research projects. In contrast, my experience and interaction with supervisors and colleagues at End-of-Life Care Research Group department at Vrije Universiteit Brussel was different. Power distance between senior and junior personnel was not obvious, and staff addressed each other by their first names but importantly there was two-way communication.

Hofstede (2011) considers societal culture as an unconscious set of values, with tendencies to prefer certain states of affairs over others, and organisational culture as an often-visible perception of the environment within an organisation. My experiences are pertinent to a description of a formal culture as I observed varying degrees of it during my engagement with different government departments, to request access to data and permission to do studies at government offices, e.g., the hospital arm of the mortality follow-back study. Apart from requesting and receiving ethics approval it was necessary to write letters of request to the Minister of Health and the Chief Executive Officer of the Regional Health Authority where the hospital is located. A letter of intent was written to the head of the medical records department at the hospital which was followed by a face-to-face meeting, and I had several meetings with the medical and surgical heads of staff including their executive assistants. This circumstance demanded preparation and persistence but yet may not be unique to the Caribbean. Despite these, what might be considered necessary formalities, it is also thanks to the cooperation of government authorities, and enthusiasm of the people whom we collaboration that these projects could be done. The relative limited availability of PhD programmes, for example, to explore palliative and end-of-life care could well contribute to research being considered a novelty or luxury activity. This of course can be a barrier, in and of itself, to doing research in the Caribbean.

BIOETHICS AND PALLIATIVE CARE IN THE CARIBBEAN

Health care providers, particularly physicians, can routinely encounter a range of ethical issues when providing care to their patients, i.e., situations involving conflict about what should be done or decisions that involves competing values. Broader palliative and end-of-life care ethical issues can include patient confidentiality and competence, resource allocation, advance directives, euthanasia and physician assisted suicide, or power of attorney. Some of which are reflected in the preceding pages of this thesis, e.g., issues related to access to palliative care including the availability and effective use of opioids for pain management (Chapters 2, 3, 4, 6 and 7), patient's autonomy and their inclusion in decision-making regarding their care and treatment, and the withholding or withdrawing of medical treatments including artificial nutrition and hydration during the last weeks or days of life (Chapter 6) and (Chapter 7) were among the ethical issues described. It is important then that health care provides possess a basic understanding about the scope of their practice in relation to ethical principles and are aware and capable of sensitively managing ethical issues, which can be considered a standard for quality of care.

6. IMPLICATIONS

RECOMMENDATIONS FOR PRACTICE

EDUCATION AND TRAINING: FORMAL CARERS

Our findings, (Chapter 7), suggest that few general practitioners (who are the primary formal care providers) have any basic formal training in palliative medicine, and there are even fewer specialist physicians. Further revelations indicated that care differed between general practitioners with training as they appeared to be proactive when communicating with the patient and patient's family or with other caregivers, and they gave opioid medications for pain management more often than those without training. The avoidance of opioids used for pain management is prevalent in developing as well as developed countries and can be linked to limited or outdated knowledge and education of their safe and effective use. The recognition of palliative medicine and palliative care by medical, nursing and allied health boards is needed to broaden the knowledge base and widen coverage. Palliative care modules should be integrated into undergraduate medical and nursing curricula that constitute the fundamental training of graduates from these programmes. There is also need for advanced degrees in medicine and nursing at the three campuses (in Jamaica, Barbados and Trinidad and Tobago) of the University of the West Indies, and education indicators and accreditation programmes need to be developed for health care providers. Additionally, there is an urgent need for the establishment of a national or Caribbean regional specialist training pathway for initial and ongoing training in palliative care for physicians, nurses and other health care providers.

EDUCATION AND TRAINING: INFORMAL CARERS

Family members were the main informal caregivers of persons with life-limiting or life-threatening conditions who were cared for and died at a private home (Chapter 6) and (Chapter 7). Unmet needs of patients and caregivers appear to be universal in part to the lack of social support but also to a lack of opportunities to gain the knowledge and skills necessary to provide care when the need arises. Particularly for the home setting, a grassroots (community lead) initiative to address this shortcoming can involve informal caregivers actively communicating about palliative and end-of-life care issues via social media, where they can organise support groups to develop their own palliative care skills. These community initiatives should be supported with resources from governmental and non-governmental sources (i.e., joint ventures) to facilitate standardisation of information and skills, e.g., physicians, nurses or grief counsellors can mentor caregivers during training sessions.

Research suggested that volunteers contribute positively to palliative care goals. The involvement of volunteers can extend the range of services, often beyond the opening hours of formal care provision, and they can operate within their own communities, work directly at the homes of patients and their families, or at a central community setting. Activities undertaken by volunteers can include practical patient care like nutrition and grooming or transporting patients and their families to and from appointments, social support or companionship or emotional support when taboo or difficult issues require discussion including bereavement support for family members.

However, it is possible that volunteering is dormant in our communities in Trinidad and Tobago. Apart from religious faiths that do organise volunteer groups for their different activities and projects, volunteers and volunteering are not obvious. In fact, a survey done by a volunteer organisation in Trinidad and Tobago in 2016 indicated that the post popular activities for their volunteers were mentorship and tutoring, raising awareness about social issues and participating in conservation of the environmental. The challenges reside not only in identifying possible volunteers to participate in palliative and end-of-life care activities in their communities, (activities they may be unfamiliar with), and how to sustain their interest and motivation to continue volunteering. But also, to convince clients (patients and their families) to open their doors to a large number of volunteers. These may be challenges of most volunteer groups or organisations, but it may be the case that sourcing the number of volunteers needed for community palliative care services may not be achievable in the short-term. A possible alternative would be to focus on family and friends, forming networks among them as they are likely to be already engaged with the concept of ‘giving of their time’ in the service of palliative care.

RECOMMENDATIONS FOR POLICY

NATIONAL PALLIATIVE CARE POLICY

A national palliative care policy which can accommodate civil society and local government initiatives, should be developed and implemented. The World Health Organisation and other international advocates for palliative care have extensively recommended the need for national health policies in countries where palliative care is underdeveloped. Trinidad and Tobago and many other Caribbean nations are signatories to the 67th World Health Assembly (WHA) held in Switzerland in 2014. Ministers of Health agreed to facilitate national action that will reduce barriers to the availability and access to palliative care. The aim of a national policy would be to integrate palliative and end-of-life care into all national health plans and policies, e.g., cancer, non-communicable diseases, infectious diseases (HIV/AIDS and tuberculosis) and paediatrics, and to develop national palliative care standards.

SCALE UP PALLIATIVR CARE SERVICES

Current service provision needs to be scaled up and a public health model to palliative care should be adopted. Information from our place of death studies, (Chapter 3) and (Chapter 4), indicated that about thirty percent of deaths nationally occur at a private home. This suggests that there is great need for home care services, but these services must be coordinated to enable continuity of care. The capacity to expand palliative care services in communities exists. Excluding main government hospitals there are over 100 health centres and health facilities (an enhanced health centre offering additional services) that cater for the delivery of primary health care. A practical start could be to include palliative care as a function of primary health care at strategically (according to geography or population density) located health centres. This can be done in phases to form a national network over time. General practitioners are necessary in this initiative as our mortality follow-back study, (Chapter 6) and (Chapter 7), indicated that they are the main formal palliative care providers and they play a key role in care coverage. Additionally, a core multidisciplinary palliative care team in each of the five Regional Health Authorities can be established to provide support to general practitioners in the community.

INVEST IN EDUCATION AND AWARENESS

From our study, (Chapter 7), physicians with formal palliative care training did make different treatment and medical end-of-life decisions than those who had no such training. Also, information from, (Chapter 6), indicated that informal caregivers including family members were the main carers at the home setting, but their ability to provide appropriate care is unknown and it is likely that most have to training. Therefore, for a successful initiative it is essential that politicians, social activists, health care professionals and the general public are made aware about the current circumstances of dying from life-limiting and life-threatening conditions, but also about the benefits of palliative care to the patient, family members and care providers.

INVEST IN PALLIATIVE CARE SERVICES WITH FUNDING

Evidence has shown that health care costs can be reduced and the quality of patient and family outcomes improved by the early integration of palliative care services in managing patients with life-limiting or life-threatening conditions. For example, as recommended by the World Health Organisation, the Ministry of Health can oversee financing mechanisms necessary to develop palliative care services. This can include a finance subgroup comprised of palliative care providers, health economists, health system managers from each Regional Health Authority, and social service providers. Government should review existing funding and service delivery models to determine the cost of delivering palliative care at the different settings.

UPDATE AND AMEND DANGEROUS DRUGS ACT

The “Dangerous Drugs Act” in Trinidad and Tobago was last updated in 2007, this document’s purpose is to restrict the use of narcotic drugs, but by extension the medical use of opioids for pain management is also restricted. Findings from our scoping review (Chapter 2), and our mortality follow-back study, (Chapter 6) and (Chapter 7), did indicate low use of and access to opioids for medical purposes as the medical opioid consumption in 2013 was 1–10 mg morphine equivalents/capita/year. A government drug policy subgroup to review the medical use of opioids for pain management can be formed. Subgroup members should include, drug regulators, pharmacologists and pharmacists, law enforcement authorities, and if necessary national and international pain, and palliative care experts and may include representatives from the International Narcotics Control Board (INCB). The purpose here includes a review and as needed revision of the narcotic control laws and regulations that govern importation, registration, storage, distribution, dispensing, accountability, pricing, and prescribing practices to ensure the adequate availability, accessibility, and affordability of essential palliative care medicines including oral morphine.

INVEST IN QUALITY OF DEATH CERTIFICATION AND DEATH CERTIFICATE DATA

Death certificates can be a useful research tool. Data from our studies, (Chapters 3, 4, 6 and 7), remarked on some deficits of the death certificate form used to register a death. We observed inconsistency in quality of completion and absence of some necessary information that limits its use as a useful source of routine data in monitoring quality end-of-life care. Other sociodemographic information that is currently not on death certificates but might be useful to record and monitor include, marital status, income bracket, education level, living arrangement and level of urbanisation of the usual place of residence of the deceased. This information is considered reliable predictors for the place of death, and modifications should be made to add these variables to death certificates. Additional information such as nationality (country of birth), or residence characteristics like municipality of death and municipality of residence, or health care system characteristics such as the number of hospital beds per 1,000 inhabitants may also be useful to include. Place of death is restricted to four categories, and groups together very diverse places, i.e., nursing homes, private hospitals, hospices and geriatric homes, which can hinder the evaluation of end-of-life care policies that uses death certificates as a data source. Relevant government bodies and medical schools should invest in the quality of death certification by developing tools or increasing the skills of physicians and striving for accuracy and uniformity.

RECOMMENDATIONS FOR RESEARCH

PLACE OF DEATH

With the most recent mortality data available, we suggest further population-level place of death studies be done in resource-poor countries, including trends in the place of death in relation to palliative and end-of-life care that consider shifts in the underlying cause of death, age and sex of the deceased populations. Qualitative studies can be considered to allow a better understanding of what influences choices about place of death, including care services, social resource change, attitudes, beliefs and preferences. The preferred place of death or place of care are unknown and an understanding of such a preference would be beneficial to policy makers and government officials in order to allocate necessary resources and services. In Trinidad and Tobago, a majority of deaths indicative of a palliative care need occurred at a government hospital, (Chapter 3) and (Chapter 4), both quantitative and qualitative studies should be done to evaluate and understand the quality of care received (by patients) and delivered (by health care providers) at this setting. Given the importance of informal palliative care indicated by our findings, (Chapter 6), future studies also need to focus on caregiver needs and experiences, particularly at the private home setting. Longitudinal studies that cover more than the time period immediately before death could also be considered.

COST IMPLICATIONS OF PROVIDING PALLIATIVE AND END-OF-LIFE CARE

With the current trend of an aging population and prevalent chronic disease, the need for palliative care services at different settings should be assessed. Current services should be systematically evaluated to get a better understanding of the costs (e.g., economic, and human resource) of providing palliative care, and the out-of-pocket costs to those that use the services. Concurrently, an evaluation of the care provided at government hospitals (that can be recognised as palliative and end-of-life care) should be done. Data can be reconciled to better understand where the demands for resources are to efficiently build and allocate needed services.

INTERVENTION STUDIES

Interventions that target some of the specific needs surrounding palliative and end-of-life care in Trinidad and Tobago are needed, e.g., family and caregiver training and support programmes, and death education programmes for the general public. This requires two types of research. Firstly, robust public health (health promotion) research focusing on the development of new or adapted interventions, applying the necessary implementation science perspective and involving the various relevant stakeholders including; communities and neighbourhoods, civil society organisations, health and allied health care providers and government agencies. Secondly, research that applies experimental designs that will allow drawing conclusions about causality of interventions and their mechanisms of action on relevant outcomes. This type of research would be a major step for moving towards a more evidence-based end-of-life care programme and planning.

8.8 SAMENVATTING

1. ACHTERGROND

De nood aan palliatieve zorg is wereldwijd hoog en neemt toe met als belangrijkste oorzaken de vergrijzing van de wereldpopulatie en een toenemend voorkomen van chronische en degeneratieve medische aandoeningen. In ontwikkelde landen met een hoog gemiddeld inkomen is een substantiële vooruitgang in de ontwikkeling van palliatieve en eindelevenszorg gerealiseerd. Gesteund door robuust onderzoek op het niveau van de populatie werden belangrijke investeringen gedaan om kwaliteitsvolle eindelevensresultaten te bekomen. Zo heeft onderzoek over de sociale en klinische omstandigheden van overlijden belangrijke onderwerpen belicht zoals: toegang tot palliatieve zorg, keuze in de plaats van overlijden – privé woongelegenheden, rusthuizen of hospices – of de ontwikkeling van gepaste wetten en beleidsregels die ethische problemen zoals het ontzeggen of intrekken van zorg en zelfs medische hulp bij overlijden aankaarten. Voorts wordt palliatieve zorg beschouwd als de beste strategie in het verlichten van lijden tijdens het levenseinde en is het een belangrijke indicator voor kwaliteitsvolle zorg als het vroegtijdig in het traject van een levensbeperkende aandoening geïmplementeerd wordt.

Buiten West-Europa, het Verenigd Koninkrijk, Noord-Amerika en Australië leeft de meerderheid van mensen die doeltreffende palliatieve zorg nodig heeft maar niet krijgt of er zelfs geen toegang toe heeft, in ontwikkelingslanden of -regio’s waar de middelen beperkt zijn. *Deze beperkte middelen verwijzen naar de geringe mogelijkheid om zorg aan te bieden voor een levensbedreigende ziekte door een gebrek aan menselijke en materiële middelen en de daarbij horende diensten, inadequate scholing en training voor gezondheidswerkers, en een gebrek aan regeringsbeleidsregels om de aanbieding van palliatieve zorg te ondersteunen.* Slechts ongeveer 14% van de mensen wereldwijd die palliatieve zorg nodig heeft krijgt het ook. In het geval van kinderen leeft 98% van zij die palliatieve zorg nodig heeft in laag- en middeninkomenslanden waarbij de nood voor de helft zich in Afrika situeert. In omgevingen met beperkte middelen, bijvoorbeeld, is een belangrijke publieke gezondheidszorguitdaging het verzekeren van een minimum aan pijnverlichting of andere symptoomcontroles, psychosociaal, emotioneel en spirituele steun. In landen met een zwakke gezondheidsinfrastructuur, maar wel met een traditioneel sterke familiale steun, kan de toegang tot zorgverlening aan huis een manier zijn om kwaliteitsvolle zorg en dekking te bekomen. Het spreekt voor zich dat middelen beschikbaar voor palliatieve zorg variëren in laag- en middeninkomenslanden en dat belangrijke tradities en culturele gevoeligheden tegenover gezondheid, terminale ziekte, overlijden en dood in acht genomen moeten worden wanneer een palliatief zorgprogramma geïmplementeerd wordt. In een meerderheid van de landen met beperkte middelen en ontwikkelingslanden heeft het gebrek aan een onderzoekscultuur en infrastructuur en het gebrek aan stimuli voor onderzoeksactiviteiten ertoe geleid dat gezondheidsonderzoek als een luxe beschouwd wordt, waardoor het dan vaak gesponsord wordt door externe bronnen. Een belangrijk obstakel en aanhoudende uitdaging in de verdere ontwikkeling van palliatieve zorg in ontwikkelingslanden is het gebrek aan informatie omtrent de omstandigheden van het overlijden aan chronische en degeneratieve medische aandoeningen, hetgeen een grondige verkenning van hoe deze landen zorg aanbieden bemoeilijkt. Bijgevolg is het sterven aan een terminale ziekte en de daarbij horende ervaringen rond het levenseinde van patiënten, hun familie en zorgverleners, in deze landen grotendeels niet onderzocht via systematisch onderzoek.

HET ENGELSTALIGE CARAÏBISCHE GEBIED

De Engelstalige Caraïbische landen zijn twaalf gebieden met vergelijkbare (Britse) koloniale ervaringen waar Engels de officiële taal is en omvatten: Antigua en Barbuda, De Bahama's, Belize, Barbados, Dominica, Grenada, Guyana, Jamaica, Saint Kitts en Nevis, Saint Lucia, Saint Vincent en de Grenadines en Trinidad en Tobago. Deze landen zijn cultureel en sociaal met elkaar verbonden, delen gelijkaardige politieke en onderwijskundige structuren en socio-economische linken zoals de Caribische Gemeenschap, en worden door de Wereldbank geclassificeerd als bovengemiddelde tot hoge inkomenslanden. De meeste zijn eilanden en zijn lid van de Conferentie van de Verenigde Naties van Kleine Eilandstaten in Ontwikkeling en vormen een groep van landen in ontwikkeling die onderhevig zijn aan kwetsbaarheden, bijvoorbeeld: hun geografische ligging kan afgelegen zijn met een beperkte bereikbaarheid via internationale reisverbindingen en met blootstelling aan natuurlijke risico's zoals stormen; kleine bevolkingen afhankelijk van hun gelimiteerde variatie aan export van producten, beperkte toegang tot betaalbare internationale financiering hetgeen de economische activiteit kan beperken, en ze zijn bovendien extreem kwetsbaar voor exogene schok. Ze hebben ook gelijkaardige gezondheidsstructuren gebaseerd op een model dat bestaat uit een gecentraliseerd ministerie van gezondheid en perifere gezondheidsfaciliteiten. De voorziening van gezondheidszorg gebeurt door een combinatie van publieke en private voorzieningen, waarbij gezondheidsdiensten van de overheid over het algemeen gratis zijn bij het verlenen. Sinds 2013 is het Caraïbische Publieke Gezondheidsagentschap de enige gewone publieke gezondheidsvoorziener en een Caraïbische palliatieve zorgvereniging werd gesticht in 2019.

De classificatie van de Wereldbank van deze landen als bovengemiddelde tot hoge inkomenslanden is vooral gebaseerd op de berekening van het bruto binnenlands product (BBP), een indicator van welzijn en ontwikkeling die exclusief gebaseerd is op materiële rijkdom en gebruikt wordt om de levensstandaard van een maatschappij te classificeren en om de rijkdom tussen landen te vergelijken. BBP zou om die reden niet de beste indicator kunnen zijn om de levensstandaard in een land te meten omdat noch economische ongelijkheden (arm-rijk verdeling) noch maatschappelijk waarden als vrije tijd, milieukwaliteit of niveaus van gezondheid en onderwijs in acht genomen worden.

De Caraïben hebben een lange migratiegeschiedenis en er wordt geschat dat 22% van de Caraïbische populatie in het buitenland woont. Het grootste aantal immigranten van de Engelstalige Caraïben die in de Verenigde Staten wonen, komen van Jamaica, Guyana en Trinidad en Tobago. Caraïbische migranten verlaten hun thuislanden – voornamelijk emigrerend naar Noord-Amerika en het Verenigd Koninkrijk – gedreven door de zoektocht naar hoger onderwijs en de vooruitzichten van economische stabiliteit in de vorm van werk, of beter betalend werk, met betere werkomstandigheden, maar ook omdat ze zoeken naar betere en veiligere omgevingen met politieke en sociale (bv minder criminaliteit) stabiliteit en een relatief hogere levensstandaard. Desalniettemin is een gevolg van de emigratie de “hersenvlucht”, aangezien migranten dikwijls jong en geschoold zijn, velen van hen gezondheidswerkers bestaande uit in de eerste plaats verpleegkundigen gevolgd door artsen, maar eveneens ingenieurs en andere opgeleide professionelen.

SOCIODEMOGRAFISCHE VERANDERINGEN

Belangrijke epidemiologische en maatschappelijke ontwikkelingen hebben veranderingen teweeggebracht in de bevolking van het Caribisch gebied. Verbeteringen in medische technologieën en behandelingen, en vooruitgang in de volksgezondheid en toegang tot gezondheidszorg hebben geleid tot een verhoogde levensverwachting. In Latijns-Amerika en het Caribisch gebied zal de levensverwachting tussen 2025 en 2030 naar verwachting toenemen tot 80,7 jaar voor vrouwen en 74,9 jaar voor mannen. In 2017 was 13% van de bevolking 60 jaar en ouder, en tegen 2030 zal deze demografische goed zijn voor meer dan 17% van de totale bevolking in deze regio. Verwacht wordt dat de vergrijzingstrend gepaard zal gaan met een afname van de vruchtbaarheid, wat kan leiden tot drastische veranderingen in de verouderingsindex (d.w.z. de verhouding tussen ouderen en mensen onder de 15 jaar), die 142 ouderen zou kunnen bereiken voor elke 100 kinderen in 2040. De belangrijkste doodsoorzaken zijn ook verschoven van overdraagbare ziekten, bijvoorbeeld malaria en tuberculose, naar niet-overdraagbare ziekten (NCD's) zoals hart- en vaatziekten en aandoeningen. De realiteit is dat niet-overdraagbare ziekten nu de belangrijkste oorzaak van vroegtijdige sterfgevallen zijn, die bijna 50% van alle sterfgevallen van personen onder de 70 jaar vertegenwoordigen, maar van het Amerikaanse continent wordt het Caribisch gebied het zwaarst getroffen door niet-overdraagbare ziekten.

Deze ontwikkelingen vergroten de kans dat een groeiend aantal mensen zal lijden en uiteindelijk zal overlijden aan chronische aandoeningen, sterfgevallen die waarschijnlijk worden voorafgegaan door langdurige perioden van ziekte die palliatieve zorg vereisen en die veel baat zouden hebben bij palliatieve zorg. Een aantal brede en belangrijke barrières beperken echter de toegang tot palliatieve zorg, waaronder: het ontbreken van een nationaal gezondheidsbeleid en gezondheidsstelsels die palliatieve zorg als gezondheidsprioriteit opnemen, de afwezigheid van kennis van palliatieve zorg bij gezondheidswerkers en beperkte opleiding van artsen in palliatieve zorgmedicatie; en de curatieve focus in de geneeskunde op het verlengen van het leven, terwijl mantelzorg en levenskwaliteit in de nabijheid van de dood worden verwaarloosd.

PALLIATIEVE ZORG EN PIJNVERLICHTING

Kerncomponenten van universele gezondheidszorg zijn palliatieve zorg en pijnverlichting, die worden beschouwd als sleutelelementen van hoogwaardige gezondheidszorg, maar de behoefte aan palliatieve zorg en pijnverlichting is grotendeels genegeerd. Van de 56,2 miljoen sterfgevallen die in 2015 wereldwijd werden geregistreerd, ervoer 45% ernstig gezondheidsgerelateerd lijden en stierf mogelijk met onderbehandelde pijn, 80% daarvan was afkomstig uit ontwikkelingsregio's waar palliatieve zorg en pijnverlichting schaars of niet aanwezig zijn. Minder dan 15% van de wereldbevolking woont in een land met een hoog inkomen, maar ze consumeren meer dan 90% van de opioïde analgetica. De jaarlijkse distributie van morfine is bijvoorbeeld meer dan 68.000 mg per patiënt die palliatieve zorg nodig heeft in Canada en 55.000 mg per patiënt in de Verenigde Staten van Amerika, maar slechts 5 mg per patiënt die palliatieve zorg nodig heeft in Haïti. In veel ontwikkelingslanden en arme regio's van de wereld is de toegang tot medische opioïde analgetica inderdaad beperkt of afwezig. De International Narcotics Control Board (INCB) meldde dat, hoewel de algemene trend in het Caribisch gebied wijst op een toegenomen gebruik van opioïden voor medische doeleinden tussen 2001 en 2013, er aanzienlijke verschillen waren tussen de landen en de consumptie onder een adequaat niveau bleef.

Studies uitgevoerd op Caribische bevolkingsgroepen concludeerden dat de behoefte aan palliatieve zorg wordt gedreven door de vraag van een vergrijzende bevolking en toenemende morbiditeit door chronische ziekten, kanker en hiv/aids, evenals de behoefte aan gezondheidszorgbeleid, opleiding van personeel, onderwijs en toegang tot effectieve analgesie. Dit zijn overeenkomsten die enige veralgemening mogelijk maken dat het geval van één Caribisch land (Trinidad en Tobago) - d.w.z. onderzoek naar de omstandigheden van overlijden aan ziekten die wijzen op een palliatieve zorgbehoefte - van toepassing kan zijn in andere Caribische landen.

TRINIDAD EN TOBAGO

De populatie werd in 2019 geschat op 1.4 miljoen mensen, waarvan 18,2% 60 jaar en ouder was. Verwacht wordt dat tegen 2013 de populatie licht zal stijgen tot 1.41 miljoen en vervolgens zal dalen tot 1.34 miljoen in 2050. De populatie van 60 jaar en ouder zal echter naar verwachting gestaag toenemen tot 24.5% in 2030 en tot 36.5% in 2050. Trinidad en Tobago heeft van de Caribische landen een van de hoogste percentages morbiditeit en mortaliteit door niet-overdraagbare of chronische ziekten, wat naar schatting 81% van alle sterfgevallen in 2016 uitmaakt. Hart- en vaatziekten (33%), vormen van kanker (15%), diabetes mellitus (15%) en chronische aandoeningen van de luchtwegen (3%) behoorden tot de belangrijkste doodsoorzaken en zijn medische aandoeningen die wijzen op palliatieve zorgbehoeften. Palliatieve zorg in T&T werd 'geïsoleerde verstrekking van palliatieve zorg' genoemd, omdat er geen nationale toewijding is aan palliatieve zorgpraktijken en de bestaande diensten beperkt zijn, met een gebrek aan overheidssteun en sociale en financiële steun. Voorbeelden zijn een onbetrouwbare beschikbaarheid van morfine bij de nationale gezondheidsinstellingen en een klein aantal hospice- en palliatieve zorgdiensten in verhouding tot de omvang van de bevolking; inbegrepen in deze categorie was Jamaica. Beschikbare dienstverlening omvat: een door verpleegkundigen geleide thuisgebaseerde oncologie/ palliatieve zorgverlening in het oosten (RHA) in Trinidad, een afdeling voor palliatieve zorg vanuit de overheid (bestaande uit een ambulante dienst met 12 bedden en ziekenhuisconsult) in het centraal noorden (RHA) , twee niet-gouvernementele hospices met 12 bedden in het noordwesten (RHA) en in Tobago (RHA) thuisgebaseerde palliatieve zorgverlening geleid door verpleegkundigen. Een polikliniek voor palliatieve zorg gevestigd in het ziekenhuis in het zuidwesten van Trinidad (RHA) werd echter in 2019 opgeschort wegens gebrek aan personeel. Pogingen om het in 2020 nieuw leven in te blazen werden gestaakt vanwege verschuivende prioriteiten van de Regionale Gezondheidsautoriteit door de opkomst van het Coronavirus (COVID-19). In 2011 is een landelijke vereniging voor palliatieve zorg opgezet.

Naast het gebrek aan klinische infrastructuur, is er ook een gebrek aan algemene onderzoeksstructuur om innovatie en beleid op dit gebied te ondersteunen. Er zijn talloze obstakels en uitdagingen bij het doen van onderzoek in ontwikkelingslanden, en een gemeenschappelijk thema van 'een gebrek aan informatie en gebrek aan orginele studies' over bijvoorbeeld palliatieve zorg in het Caribisch gebied blijft bestaan. Omdat er een gebrek is aan gegevens van welk Caribisch land dan ook door middel van grootschalige robuuste onderzoeken die zijn uitgevoerd om de omstandigheden van overlijden te bevestigen en rond de verlening van palliatieve zorg, heb ik dit onderzoeksproject uitgevoerd omdat ik het beter wilde begrijpen en meer inzichten in het veld wilde bieden, maar vooral omdat het belangrijk is om gegevens, kennis en bewijs te genereren rond palliatieve zorg en zorg aan het levenseinde vanuit een Caribische context.

2. DOELSTELLINGEN EN ONDERZOEKSVRAGEN VAN DE STUDIE

De belangrijkste doelstellingen van dit proefschrift zijn het beschrijven van de omstandigheden waaronder personen overlijden en het beschrijven van de medische zorg en behandeling die een persoon ontving voorafgaand aan zijn overlijden in Trinidad en Tobago.

I. Het eerste doel is om de kennis en kennishiaten die zijn gedocumenteerd in de literatuur over palliatieve zorg en zorg aan het levenseinde in de Engelstalige Caribische regio te identificeren en uitvoerig te bekijken. De volgende onderzoeksvragen worden beantwoord:

1. Wat zijn de gemeenschappelijke thema's die gedocumenteerd worden in de literatuur over palliatieve zorg en zorg aan het levenseinde in het Engelstalige Caribisch gebied? Wat zijn de belemmeringen en voorgestelde verbeteringsstrategieën om palliatieve zorg verder te ontwikkelen in Engelstalige Caribische landen?

II. Om het gebrek aan onderzoeksgegevens te compenseren, is het tweede doel het onderzoeken en gebruiken van beschikbare routinematig verzamelde administratieve gegevens op bevolkingsniveau over sterven in Trinidad en Tobago. De volgende onderzoeksvragen worden beantwoord:

1. Waar sterven mensen in Trinidad en Tobago? Wat zijn de sociale omstandigheden en kenmerken die verband houden met hun plaats van overlijden?
2. Wat is de trend in de plaats van overlijden en wat zijn de implicaties voor zorg aan het levenseinde en de beleidspraktijk gerelateerd aan trends?

III. Het derde doel is het genereren van betrouwbare en representatieve gegevens en inzicht met betrekking tot zorg rond het levenseinde en medische beslissingen rond het levenseinde van niet-acute sterfgevallen in Trinidad en Tobago, en het identificeren en beschrijven van belangrijke verschillen in zorg rond het levenseinde en besluitvorming tussen sociodemografische en klinische groepen.

De volgende onderzoeksvragen worden beantwoord:

1. Is het haalbaar om een representatief nationaal onderzoek uit te voeren door een vragenlijst over palliatieve zorg en zorg aan het levenseinde aan te passen aan de sociaal-juridische context van Trinidad en Tobago?
2. Wat zijn de kenmerken van palliatieve zorg, zorg aan het levenseinde en behandeling en medische besluitvorming aan het levenseinde in Trinidad en Tobago?
3. Wat zijn de kenmerken van zorgverleners die palliatieve zorg en zorg aan het levenseinde verlenen aan mensen die thuis overlijden in Trinidad en Tobago?
4. Wat is het sociaal-demografische en klinische profiel van patiënten die thuis in Trinidad en Tobago palliatieve zorg en zorg aan het levenseinde krijgen? Wat zijn de kenmerken en incidentie van verschillende soorten medische beslissingen rond het levenseinde die aan het levenseinde worden genomen voor personen die thuis overlijden?
5. Is er in Trinidad en Tobago een verschil in de besluitvorming over medische zaken rond het levenseinde, afhankelijk van de formele palliatieve zorg opleiding van artsen?

3. METHODEN

SCOPING LITERATUURONDERZOEK (ONDERZOEKSDOEL I.1)

Een systematisch scoping literatuuronderzoek werd uitgevoerd omdat we het onderwerp van palliatieve zorg en levenseindezorg in Engelssprekende Caribische landen uitgebreid wilden onderzoeken. Methodologische details zijn te vinden in (Hoofdstuk 2)

ANALYSE OP POPULATIENIVEAU VAN ROUTINEMATIG VERZAMELDE ADMINISTRATIEVE EN AANVULLENDE GEZONDHEIDSGEGEVENS (ONDERZOEKSDOELEN II.1-2)

We hebben analyses op populatieniveau uitgevoerd van routinematig verzamelde gegevens uit overlijdensakten en aanvullende gezondheidsgegevens.

I. PLAATS VAN OVERLIJDEN IN 2010. Op het moment dat de studie werd uitgevoerd, 2017, was het meest recente beschikbare jaar van voltooide mortaliteitsgegevens 2010 (N=10,221). Het nationale overlijdensregister het Centraal Bureau voor de Statistiek (CSO) verstrekte ook aanvullende census gegevens (census data) (gemeenschapsclassificatie van verstedelijking), en gegevens over het percentage van de bevolking dat in 2010 in een stedelijke omgeving woonde. Het Ministerie van Gezondheid verstrekte gegevens over gezondheidsmiddelen, d.w.z. het aantal ziekenhuisbedden van de overheid (n=2009) en het aandeel van bedden per regionale gezondheidsautoriteit (RHA): Noord-West, Noord-midden, Zuid-West, Oost en Tobago.

II. TRENDANALYSE VAN PLAATS VAN OVERLIJDEN 1999 – 2010. De studie werd uitgevoerd in 2018 en als gevolg van vertragingen bij de codering waren volledig ingevulde en betrouwbare datasets alleen beschikbaar voor de jaren 1999 tot en met 2010. Demografische kenmerken van overledenen (N=118,703), waaronder het jaar, de leeftijd, het geslacht en de belangrijkste onderliggende doodsoorzaak, werden uit de registers geëxtraheerd. Een subcategorie van personen die overleden aan enkele van de meest voorkomende chronische levensbeperkende aandoeningen die indicatief zijn voor palliatieve zorg werden in aanmerking genomen.

POPULATIENIVEAU MORTALITEIT FOLLOW-UP STUDIE OP BASIS VAN OVERLIJDENSAKTEN (ONDERZOEKSDOEL III.1-5)

In 2018 werd een mortaliteitsstudie op populatieniveau uitgevoerd op basis van een representatieve steekproef van overlijdensakten van overlijdens die thuis hadden plaatsgevonden. Het steekproefkader werd verkregen uit overlijdensakten die op het CSO werden gesampled. Er werd gebruik gemaakt van een mortaliteitsstudie omdat het een efficiënte onderzoeksmethode is om robuuste populatiegebonden informatie te verzamelen over de laatste dagen of maanden van het leven. Ethische goedkeuring voor deze studie werd verleend door het Ministerie van Volksgezondheid van Trinidad en Tobago (geen dossiernummer beschikbaar: Het ministerie houdt geen catalogus bij van goedkeuringen die voor onderzoek zijn verleend). De Trinidad and Tobago Medical Association was een neutrale adviseur en partner bij de planning en uitvoering van deze studie. Hierover zijn drie rapporten geschreven.

I. ONTWIKKELING VAN DE VRAGENLIJST. Er werd een vragenlijst ontwikkeld (hoofdstuk 5) en cognitief getest om op een gestandaardiseerde manier op bevolkingsniveau informatie te verzamelen over de medische kenmerken van palliatieve zorg en zorg rond het levenseinde (d.w.z. de zorg die in de laatste 30 dagen voor het overlijden wordt verleend), en de omstandigheden van het sterven. Naar het voorbeeld van een vragenlijst die oorspronkelijk in 1990 in Nederland werd ontwikkeld en tussen 1997 en 2016 in licht aangepaste versies in andere landen werd gebruikt, werd onze vragenlijst aangepast door middel van cognitieve tests en face validatie om na te gaan of de vragenlijst geschikt en relevant was voor de context van Trinidad en Tobago. De vragenlijst werd gebruikt in de mortaliteitsstudie die twee rapporten opleverde.

II. PALLIATIEVE EN LEVENSEINDEZORG, (Hoofdstuk 6) en de andere MEDISCHE BESLISSINGEN BIJ HET EINDE VAN HET LEVEN, (Hoofdstuk 7). Een random steekproef van inwoners van Trinidad en Tobago van 18 jaar of ouder, die tussen 1 maart en 31 augustus 2018 in een privéwoning zijn overladen, werd getrokken uit de overlijdensakten van het CSO; de stoekproeffractie was 1 op 2. De huisarts die elk overlijden in de steekproef certificeerde, werd per post uitgenodigd om een vragenlijst in te vullen over de zorg aan het einde van het leven voor dit specifiek geval. In totaal werden 752 sterfgevallen gesampled. De neutrale derde partij was bij de postprocedure betrokken als intermediair tussen de reagerende huisartsen, de onderzoekers en het CSO om de anonimiteit van de huisartsen te bewaren en te garanderen dat ingevulde vragenlijsten nooit aan een bepaalde patiënt of arts konden worden gekoppeld.

4. BELANGRIJKSTE BEVINDINGEN

DEEL I – IDENTIFICEREN VAN KENNIS EN HIATEN IN DE LITERATUUR

OVERZICHT VAN DE LITERATUUR

We voerden een scoping review uit (Hoofdstuk 2) om de stand van kennis te beschrijven zoals beschreven in de gepubliceerde academische en grijze literatuur over palliatieve zorg en levenseindezorg in Engelstalige Caribische landen, een groep van landen met weinig middelen die een vergelijkbare culturele en historische achtergrond delen, inclusief vergelijkbare economische, milieu- en onderzoeksuitdagingen. Een systematische zoektocht identificeerde slechts vijfentwintig gepubliceerde artikelen die de jaren 1991 tot 2015 omspanden, waarvan tien originele studies, wat de schaarste weerspiegelt van (empirische) informatie die kan worden gebruikt om de volksgezondheidspraktijk met betrekking tot palliatieve zorg en levenseindezorg te informeren en te sturen. We identificeerden vijf belangrijke thema's in de literatuur: 1) sociaaleconomische en culturele normen over terminale ziekte en dood die de ontwikkeling en levering van palliatieve zorg en zorg aan het einde van het leven beïnvloeden;

2) beperkte toegang tot opioïden voor medisch gebruik; 3) beperkte palliatieve zorgdiensten in vergelijking met de behoefte; 4) onvervulde behoeften aan palliatieve zorg; en 5) een gebrek aan relevante onderzoeksactiviteit in de regio. Enkele veel voorkomende belemmeringen voor de ontwikkeling van palliatieve zorg in het Engelssprekend Caribisch gebied zijn: ontoereikende gezondheidszorgsystemen die geen universele dekking bieden en die weinig opties bieden met betrekking tot ondersteunende diensten in de palliatieve zorg voor patiënten met levensbeperkende of levensbedreigende aandoeningen; een gebrek aan gedocumenteerd beleid en verouderde opvattingen over het effectieve gebruik van opioïde pijnstillers; beperkte bekendheid over en toegang tot beschikbare palliatieve zorgdiensten werkt onvervulde behoeften in de hand; slechte communicatie tussen zorgverleners, patiënten en hun familie belemmert accurate informatie-uitwisseling; culturele taboes en attitudes van het publiek ten opzichte van terminale ziekte en de dood worden sterk beïnvloed door religieuze overtuigingen; en de afwezigheid van een onderzoekscultuur.

Vergeleken met andere ontwikkelingslanden in Latijns-Amerika of Afrika zijn onze bevindingen niet uniek, aangezien het gebrek aan empirische informatie over het aanbod van en de toegang tot palliatieve zorg veel voorkomende problemen zijn in landen en regio's die over weinig middelen beschikken. Onze studie identificeerde echter wel mogelijkheden voor verbetering in de Engelssprekende Caraïben voor de overlappende kwesties van praktijk, beleid en onderzoek en biedt een conceptueel kader voor verder onderzoek.

DEEL II – GEBRUIK VAN BESCHIKBARE ADMINISTRATIEVE EN ROUTINEMATIG VERZAMELDE GEGEVENS VOOR STUDIES OP POPULATIENIVEAU IN EEN CONTEXT MET WEINIG MIDDELEN

WAAR STERVEN MENSEN IN TRINIDAD EN TOBAGO

In (Hoofdstuk 3) analyseerden we routinematig verzamelde gegevens van overlijdensakten in Trinidad en Tobago. We hebben een dataset voor het jaar 2010 verkregen van het nationale overlijdensregister. Op het moment van de studie, 2010 was het meest recente beschikbare jaar. Aanvullende gezondheidsgegevens warden verkregen van het Ministerie van Volksgezondheid en opgenomen in onze analyses. het grootste deel van de sterfgevallen (55.4%) vond plaats in overheidsziekenhuizen; terwijl (29,7%) plaatsvond in een particulier tehuis en (5,9%) in een verpleeghuis of een niet-gouvernementeel (particulier) ziekenhuis. Wij stelden vast dat de plaats van overlijden wordt beïnvloed door leeftij, onderliggende doodsoorzaak, geslacht, urbanisatieniveau en ras/etniciteit. Overlijden thuis wordt waarschijnlijker naarmate de leeftijd toeneemt. In vergelijking met de referentiegroep van 18-69 jaar is het op de leeftijd van 70-89 jaar (OR 1,91, 95% CI 1,73 tot 2,10) en de leeftijd van 90-hoogste jaar (OR 3,63, 95% CI 3,08 tot 4,27) waarschijnlijker om thuis te overlijden. Thuis overlijden was ook waarschijnlijker voor mensen met ziekten van het zenuwstelsel (OR 1,44, 95% CI 1,08 tot 1,93) in vergelijking met de referentiegroep, mensen die sterven aan hart- en vaatziekten, maar minder waarschijnlijk voor mensen met kanker (OR 0,85, 95% CI 0,74 tot 0,97), cerebrovasculaire ziekten (OR 0,61, 95% CI 0,51 tot 0,72) of aandoeningen van de luchtwegen (OR 0,74, 95% CI 0,59 tot 0,91) dan de referentiegroep. We stelden ook vast dat sterven aan ziekten van het zenuwstelsel (OR 0,49, 95% CI 0,37 tot 0,66) geassocieerd was met een lagere kans om in een overheidsziekenhuis te sterven.

Vergeleken met vrouwen hebben mannen een grotere kans om in een overheidsziekenhuis te sterven (OR 0,87, 95% CI 0,80 tot 0,94), en wonen in een landelijk gebied werd geassocieerd met een grotere kans om thuis te sterven (OR 1,51, 95% CI 1,35 tot 1,70) en een kleinere kans om in een overheidsziekenhuis te sterven (OR 0,77, 95% CI 0,69 tot 0,86). Onze rapportage van de verschillende etnische groepen is in overeenstemming met de wijze waarop deze demografische gegevens op overlijdensakten worden verzameld. Er blijkt ongelijkheid te bestaan tussen etnische groepen wat betreft de plaats van zorg en overlijden, aangezien de plaats van overlijden van mensen die als etnisch blank worden gecategoriseerd verschilt van elke andere ras/etnische groep: 48,8% stierf thuis en 17,1% in een verpleeghuis of particulier ziekenhuis, wat meer was dan elke andere etnische groep, terwijl 29,3% in een overheidsziekenhuis stierf, het minste van elke andere groep. Een regressiemodel met de variabele ras/etniciteit (61,1% van de gegevens ontbraken) als onafhankelijke variabele, met controle voor leeftijd, geslacht en doodsoorzaak, bevestigde een significant lagere kans om thuis te sterven voor zwarte (OR 0,51, 95% CI 0,27 tot 0,98) dan voor etnisch blanke mensen en een grotere kans om in het ziekenhuis te sterven voor Oost-Indische (OR 2,32, 95% CI 1,14 tot 4,71) en zwarte (OR 3,33, 95% CI 1,64 tot 6,74) in vergelijking met etnisch blanke mensen.

Deze studie toont aan dat het zelfs in omgevingen met weinig middelen mogelijk kan zijn om gegevens uit overlijdensakten en aanvullende gezondheidsgegevens te gebruiken om de plaats van overlijden en de variatie daarin naar sociodemografische en klinische kenmerken te bestuderen. De bevindingen suggereren dat in verschillende zorgomgevingen aandacht nodig is voor het monitoren van de beschikbaarheid, betaalbaarheid en toegang tot goede zorg aan het einde van het leven, maar ook voor het garanderen van gelijkheid (bv. naar ethische groepen en klinische presentatie) in deze factoren.

DE PLAATS VAN OVERLIJDEN IN DE LOOP VAN DE TIJD

In (Hoofdstuk 4) hebben we dieper ingezoomd op de tijdsgebonden trends inzake de plaats waar mensen komen te overlijden omdat de plaats van overlijden een belangrijke impact kan hebben op de kosten van de gezondheidszorg. Dit geldt zeker ook voor kleine landen die het met weinig middelen moeten stellen. Het is namelijk aangetoond dat de kosten voor levenseindezorg binnen het ziekenhuis hoger liggen dan de kosten voor levenseindezorg buiten het ziekenhuis. Voor de jaren 1999 tot en met 2010 konden we beschikken over volledig ingevulde en betrouwbare datasets van het totale aantal waargenomen sterfgevallen (N = 118.703). De drie belangrijkste geregistreerde doodsoorzaken in deze periode, gerangschikt volgens frequentie, waren hart- en vaatziekten, diabetes mellitus en maligniteiten. Een subcategorie van personen die zijn overleden aan enkele van de meest voorkomende levensbekortende aandoeningen werd eveneens geïncludeerd. Het gaat hierbij om de volgende ziekten en hun overeenkomstige International Classification of Diseases 10 (kortweg ICD10) codering: hart- en vaatziekten (I00-I52, I70-I99), kanker (C00-C97), aandoeningen van de luchtwegen (J00-J99), ziekten van het zenuwstelsel (G00-G99), cerebrovasculaire aandoeningen (I60-I69) en diabetes mellitus (E08-E13).

Het aantal sterfgevallen door kanker is in de periode 1999-2010 gestegen en het aandeel sterfgevallen door hart- en vaatziekten is in diezelfde periode gedaald. We stelden vast dat het aandeel sterfgevallen in overheidsziekenhuizen sterk toenam, van 48,9% in 1999 tot 55,4% in 2010. Het aantal sterfgevallen in privéwoningen daalde echter sterk, van 38,7% tot 29,7% in dezelfde periode. In de loop van de tijd waren de verschuivingen inzake de sterfgevallen in ziekenhuizen en tehuizen nog opvallender voor die sterfgevallen, die het gevolg waren van aandoeningen die, volgens de literatuur, wijzen op een behoefte aan palliatieve zorg. Sterfgevallen ten gevolge van kanker toonden de meest opvallende verschuiving aan: het aantal sterfgevallen thuis daalde van 51,6% in 1999 tot 31,2% in 2010, maar het aantal sterfgevallen in ziekenhuizen steeg in dezelfde periode van 38,4% tot 54,7%. Het aandeel sterfgevallen in een verpleeghuis of een particulier ziekenhuis daalde (van 7,1% naar 5,9%), terwijl het aantal sterfgevallen op andere plaatsen, inclusief particuliere bejaardentehuizen, steeg (van 5,3% naar 8,9%). Wij vergeleken zowel de waargenomen als de (voor leeftijd en geslacht) gestandaardiseerde cijfers voor de periode 1999 tot 2010, maar konden daarbij weinig variatie vaststellen.

Deze studie toonde een sterke trend richting "ziekenhuisopname bij overlijden" aan die vergelijkbaar is met de trends die in de tweede helft van de 20e eeuw in veel ontwikkelde landen en landen die op meer middelen kunnen rekenen, werden waargenomen. De laatste twee decennia werd daar echter een omgekeerde trend waargenomen waarbij in veel van die landen minder sterfgevallen in het ziekenhuis voorkwamen. Dit werd toeschreven aan hun specifiek beleid inzake palliatieve zorg of zorg aan het levenseinde. De aanhoudende trends in Trinidad en Tobago suggereren dan ook de behoefte aan een nationaal beleid voor palliatieve zorg en zorg rond het levenseinde die rekening houdt met zowel het toenemend aantal mensen dat binnen overheidsziekenhuizen om zorg verzoekt als met beschikbare alternatieven voor zorg en het kunnen sterven buiten de muren van het ziekenhuis.

Deel III – HET GENEREREN VAN NIEUWE DATA EN HET ONDERZOEKEN VAN DE OMSTANDIGHEDEN INZAKE LEVENSEINDEZORG EN HET STERVEN AAN ERNSTIGE AANDOENINGEN AAN DE HAND VAN RETROSPECTIEVE MORTALITEITSSTUDIE (MORTALITY FOLLOW-BACK STUDY)

ONTWIKKELING VAN VRAGENLIJSTEN TEN BEHOEVE VAN EEN RETROSPECTIEVE MORTALITEITSSTUDIE (MORTALITY FOLLOW-BACK STUDY)

De empirische data voor deze studie, (zie Hoofdstuk 5), zijn voornamelijk gebaseerd op interviews met 18 artsen met een verschillende achtergrond, onder wie huisartsen, oncologen, gerontologen, internisten en clinici binnen de palliatieve geneeskunde. Veertien artsen uit Trinidad en vier uit Tobago namen vrijwillig deel aan face-to-face interviews met als doel een gezichts- en inhoudsvalide vragenlijst te ontwikkelen. Deze interviews resulteerden in de volgende belangrijke wijzigingen aan de initiële vragenlijst: de toevoeging van een definitie van palliatieve zorg en instructies voor het invullen van de vragenlijst; aanpassingen in vraagformulering, woordkeuze, volgorde van vragen, antwoordopties en lay-out; en schrapping dan wel toevoeging van vragen en antwoordopties.

Onze studie toont aan dat het uitdaging vormt om in arme landen of ontwikkelingslanden onderzoek naar de Volksgezondheid te doen, maar toch mogelijk is om hiertoe bestaande onderzoeksinstrumenten uit rijke landen te gebruiken. Het is echter uiterst belangrijk om de nodige socioculturele en klinische aanpassingen te maken om deze instrumenten binnen de specifieke context te implementeren.

PALLIATIEVE ZORG EN ZORG AAN HET LEVENSEINDE VOOR PATIËNTEN DIE NIET PLOTSELING IN DE THUISSITUATIE OVERLIJDEN

(Hoofdstuk 6) beschrijft de bevindingen van deze studie met betrekking tot de palliatieve zorg en de zorg aan het levenseinde die patiënten tijdens het levenseinde hebben gekregen, voorafgaand aan hun overlijden thuis. Er werden driehonderdennegen vragenlijsten verstuurd die 21% van alle geregistreerde sterfgevallen van volwassenen weergeven. Het gaat om geregistreerde sterfgevallen die plaatsvonden in een particuliere woning en waarvan de overlijdensakten beschikbaar waren gedurende de onderzoeksperiode. De respons op de enquête was 31% (*N* = 96). Van deze sterfgevallen betrof 76% geen onverwacht overlijden, maar (27,4%) van deze mensen die niet onverwacht waren overleden, kampten met aandoeningen die duidden op een behoefte aan palliatieve zorg en toch geen palliatieve zorg kregen. Er werden geen significante verschillen voor geslacht (*P* = 0,12), leeftijd (*P* = 0,62), of doodsoorzaak (*P* = 0,85) opgemerkt tussen de overledenen in de respons-steekproef in vergelijking met alle onderzochte sterfgevallen.

Over het algemeen vervulden de familieleden en de huisarts van de patiënt de rol van meest betrokken zorgverleners. De familieleden verleenden palliatieve zorg in (60,3%) van de gevallen en verleenden uitsluitend palliatieve zorg in 22 (30%) gevallen. Huisartsen waren eveneens betrokken bij de zorg in (39,7%) van de gevallen. Familieleden en huisartsen nemen een groot deel van de zorg op hun schouders en vervullen een belangrijke rol voor hun stervende familieleden en patiënten, ongeacht de aard van de ziekte. Er wordt niet vaak gebruik gemaakt van gespecialiseerde palliatieve zorg, aangezien uit de resultaten blijkt dat slechts (6,8%) van de patiënten voor hun overlijden palliatieve zorg gekregen heeft. In de laatste 30 dagen van het leven waren, naast huisartsen, vooral familieleden (89,0%), verpleegkundigen (31,5%) en medisch specialisten (15,1%) het vaakst betrokken bij de zorg voor de patiënt. In de laatste 30 dagen van het leven bestonden de meest voorkomende behandelingen uit het toedienen van pijnstillers (53,4%), antibiotica (34,2%) en kunstmatige hydratatie (26%).

Uit ons onderzoek naar de verschillen in zorg en behandeling tussen sterfgevallen ten gevolge van kanker en sterfgevallen ten gevolge van andere ziekten, bleek dat bij sterfgevallen ten gevolge van kanker de overledenen de zorg hoofdzakelijk ontvingen van familieleden (73,3%), gevolgd door huisartsen (60%) en gespecialiseerde palliatieve zorgdiensten (13,3%). Een groter aandeel van sterfgevallen door kanker kreeg pijnstillers (93,3%) dan sterfgevallen zonder kanker (43,9%), (*P* = 0,003). Huisartsen gaven prioriteit aan comfortmaximalisatie (60,3%) als belangrijkste zorgdoel in de laatste week van het leven. Het toedienen van analgetica (53,4%) was de meest voorkomende behandeling die ingezet werd om dit doel te bereiken.

Onze studie toont aan dat informele zorgverleners, in het bijzonder familieleden, de belangrijkste schakel vormen bij het verlenen van palliatieve zorg aan hun terminaal zieke familieleden in de gemeenschap. Daarom zijn programma's om familieleden op te leiden om de nodige zorg te verlenen aan het levenseinde van cruciaal belang, vooral voor landen die over weinig middelen beschikken en waar het ontbreekt aan goed opgeleide professionals.

MEDISCHE BESLUITVORMING ROND HET LEVENSEINDE BIJ NIET PLOTSELINGE STERFGEVALLEN IN DE THUISSITUATIE

Uit onze gegevens (hoofdstuk 7) blijkt dat de meeste huisartsen (69,8%) geen formele opleiding in de palliatieve zorg hadden gevolgd, d.w.z. dat palliatieve zorg geen deel uitmaakte van hun medische opleiding of postdoctoraal opleidingsprogramma. De meeste huisartsen waren van mening dat ze hun expertise in communicatie rond het levenseinde met hun patiënten (78,1%) en familieleden van patiënten (84,4%) via zelfstudie en door jarenlange ervaring hadden opgedaan. Ook voerden de meeste huisartsen (61,6%) geen gesprekken met hun patiënten over de behandelopties aan het levenseinde, al werden de partner of de familieleden van de patiënt in de meeste gevallen wel bij deze gesprekken betrokken (75,3%). Wanneer de gesprekken met de patiënt werden gevoerd, ging het meestal over gesprekken rond het geven van medicatie om pijn en symptomen te verlichten (30,1%), de patiënt te onthouden van behandelingen (13,7%) of het stopzetten van behandelingen (4,1%). Wanneer huisartsen met een formele opleiding werden vergeleken met huisartsen zonder opleiding, vonden we dat gesprekken met patiënten over het onthouden van behandelingen (25% vergeleken met 6,7%) en over het geven van medicatie om pijn of symptomen te verlichten vaker voorkwamen. De huisartsen zonder formele opleiding hadden vaker de neiging om geen enkele behandelingsoptie met de patiënt te bespreken (75,6% versus 39,3%, *p* = 0,002).

De meest voorkomende medische beslissingen aan het levenseinde waren het toedienen van morfine of een ander opioïde (20,5%) en het onthouden van kunstmatige hydratatie en voeding (6,8%). Onder de niet-behandelingsbeslissingen werden geen behandelingen stopgezet, maar levensverlengende behandelingen onthouden bij 7 (9,6%) sterfgevallen. De meest voorkomende behandelingen die aan de patiënt werden onthouden waren kunstmatige hydratatie en kunstmatige voeding (6,8%), gevolgd door beademing en cardiopulmonale resuscitatie (4,1%). In 34,2% van de gevallen werden geen medicijnen gebruikt om de symptomen van de patiënt in de laatste zeven dagen van het leven te verlichten. Morfine of andere opioïden 20,5% en diazepam of andere benzodiazepines 17,8% waren de meest voorkomende medicijnen die in deze periode werden toegediend. Wij vonden dat huisartsen die een formele opleiding in palliatieve zorg hadden gevolgd, hetzij als onderdeel van hun reguliere medische opleiding, hetzij via een postgraduaatsprogramma, meer geneigd waren om opioïden voor te schrijven of toe te dienen in de laatste zeven dagen van het leven 35,7% dan diegenen die geen formele opleiding hadden gevolgd 11,1% (*p* = 0,01).

Onze studie toont aan dat relatief weinig huisartsen een formele opleiding in de palliatieve zorg hebben gevolgd, maar de bevindingen suggereren een verband tussen opleiding in de palliatieve zorg en de waarschijnlijkheid om patiënten met opioïden te behandelen aan het levenseinde alsook om de opties voor behandeling aan het levenseinde te bespreken met de patiënt en andere zorgverleners.

5. BESPREKING VAN DE BELANGRIJKSTE BEVINDINGEN

BEPERKTE PALLIATIEVE ZORGDIENSTEN

Een terugkerend thema in ons onderzoek is de beperkte palliatieve zorg en zorg aan het levenseinde in Trinidad en Tobago. Dit lijkt het ook een gedeelde uitdaging te zijn voor andere Caribische landen. Centraal in deze uitdaging staat de toenemende behoefte aan een passende gezondheidszorg om tegemoet te komen aan de prevalentie van mensen die leven met ernstige, levensbedreigende of levensbeperkende ziekten. In combinatie met een vergrijzende bevolking die aan een reeks chronische comorbide aandoeningen lijdt, kan het sterven aan ernstige ziekten een knelpunt worden voor het nationaal gezondheidszorgstelsel. Dit scenario kan zich zowel in ontwikkelde, hoge inkomenslanden als in ontwikkelings- en lage inkomenslanden voordoen. Er zijn weinig mogelijkheden voor formele palliatieve zorgverlening. In verhouding tot het aantal mensen met chronische medische aandoeningen kunnen we concluderen dat de huidige dienstverlening tekort schiet.

ZORGSETTINGEN ROND HET LEVENSEINDE

Hoge prevalentiecijfers voor levensbeperkende en levensbedreigende aandoeningen, waaronder hart- en vaatziekten 33%, kanker 15%, diabetes mellitus 15% en chronische aandoeningen van de luchtwegen 3%, behoren tot de belangrijkste oorzaken van ernstig gezondheidsgerelateerd lijden en overlijden, en zijn stuk voor stuk medische aandoeningen die wijzen op een behoefte aan palliatieve zorg. Het zorgaanbod zal variëren naargelang van de behoefte, maar het lijkt erop dat het gezondheidszorgsysteem in de nabije toekomst steeds meer zal worden uitgedaagd om palliatieve zorg te verlenen in verschillende instellingen en settingen. Het lijkt erop dat de middelen vooral geconcentreerd zijn in overheidsinstellingen ten behoeve van de ziekenhuizen en dat er weinig aandacht en middelen beschikbaar zijn voor alternatieven. In alle settingen kunnen de financiële kosten van levenseindezorg aanzienlijk oplopen, maar het is gebleken is dat de kosten voor ziekenhuiszorg, met name acute ziekenhuiszorg, hoger zijn dan de kosten voor de zorg buiten het ziekenhuis. Zorg(diensten) in bejaardentehuizen of instellingen voor begeleid wonen zijn op dit moment nog niet in het onderzoek opgenomen, maar uit onze trendstudie over de plaats van overlijden (hoofdstuk 7) blijkt dat het aantal sterfgevallen in deze instellingen toeneemt. Dit scenario illustreert de behoefte aan breed toegankelijke palliatieve zorgdiensten die geïntegreerd zijn in het gezondheidszorgsysteem volgens een passend zorgmodel, bijvoorbeeld via een palliatieve zorgafdeling in elk groot overheidsziekenhuis, of gemeenschapszorg die thuiszorg kan faciliteren, of een combinatie van beide. Niettemin dienen beleidsmakers en besluitvormers in de gezondheidszorg hier dringend aandacht aan te besteden.

ROL VAN INFORMELE ZORG

Een meerderheid van de sterfgevallen in Trinidad en Tobago vond plaats in een overheidsziekenhuis, maar de prevalentie en het type palliatieve zorg dat werd ontvangen door degenen die deze zorg nodig hadden, is onbekend. Met andere woorden, overheidsziekenhuizen zijn misschien niet de plaats bij uitstek om palliatieve zorg en zorg rond het levenseinde te ontvangen. Maar door een gebrek aan alternatieven is het mogelijk dat de zorgbehoevenden denken dat overheidsziekenhuizen de enige instellingen zijn die hen het verwachte niveau van zorg kunnen bieden. Hoewel onze bevindingen zijn berekend op basis van gegevens van 2010 en eerder, mogen we aannemen dat een aanzienlijk aantal sterfgevallen nog steeds in een privéwoning plaatsvindt. Met de weinige en beperkte beschikbare diensten blijft het een uitdaging om palliatieve zorg en zorg rond het levenseinde te bieden aan al diegenen die dit in de thuissituatie nodig hebben.

Van alle sterfgevallen wereldwijd zouden naar schatting 74% van de mensen met een levensbeperkende of levensbedreigende aandoening baat kunnen hebben bij palliatieve zorg, maar waar de bestaande formele palliatieve zorg tekort schiet, is er wel gelegenheid voor de zorg die verleend wordt door informele zorgverleners, zoals mantelzorgers. Met ‘mantelzorger’ doelen we op de persoon die onbezoldigd hulp verleent aan of regelt voor een geliefde, familielid, vriend of vreemde (vrijwilliger) omdat deze laatste door ziekte of handicap niet meer in staat is om voor zichzelf te zorgen. Mantelzorgers, met name familieleden, van personen met een levensbeperkende of levensbedreigende aandoening leveren een belangrijke bijdrage aan de zorg voor deze patiënt. Hun betrokkenheid kan de algemene levenskwaliteit van hun dierbaren verbeteren door dagelijkse activiteiten zoals eten, hygiëne en verzorging mogelijk te maken of door emotionele steun te bieden. Hun belangrijke rol als eerstelijnszorgverleners is duidelijk weerspiegeld in de bevinding dat zij diegenen zijn die de medicatie toedienen (indien ze daarvoor opgeleid zijn), zoals medicatie ter pijnbestrijding, en de effectiviteit ervan controleren door te letten op tekenen van onderbehandeling, of omdat ze optreden als zorgcoördinator en als brugpersoon tussen de patiënt en de zorgverleners communiceren over de gezondheidstoestand van de patiënt. Bovendien blijkt palliatieve thuiszorg een positieve invloed te hebben op de kwaliteit van de zorgresultaten, zoals minder last van symptomen, een betere kwaliteit van de zorg en minder kosten voor de gezondheidszorg aan het levenseinde.

In ontwikkelingslanden en landen die over weinig middelen beschikken, waar de palliatieve zorg onderontwikkeld is en waar het vangnet van een responsief socialezekerheidsstelsel wellicht niet beschikbaar is, moet gezocht worden naar levensvatbare en alternatieve oplossingen om palliatieve zorg te bevorderen. De volksgezondheidsbenadering van palliatieve zorg in de Indiase deelstaat Kerala, waarbij gebruik wordt gemaakt van modellen van gemeenschapsparticipatie, en waar diensten door de gemeenschap worden gefinancierd en gedeeltelijk worden ondersteund door vrijwilligerswerk, kan een geschikt model zijn om na te volgen. Ze zullen de behoefte aan en de rol van formele palliatieve zorg en zorg rond het levenseinde echter niet vervangen. Daarom kan een volksgezondheidsmodel worden overwogen, waarin componenten van gespecialiseerde en generalistische palliatieve zorgdiensten, samen met palliatieve zorgprojecten binnen gemeenschappen, wijken en buurten, zijn opgenomen. Tot op zekere hoogte zullen er wellicht al enkele elementen van deze componenten ingang hebben gevonden in bepaalde gemeenschappen van Trinidad en Tobago. Het is mede door het bestaan van deze gemeenschapsstructuren dat de nationale gezondheidsdiensten een verantwoordelijkheid hebben om deze gemeenschappen verder te faciliteren en stimuleren, om ook op die manier de functie van een volksgezondheidsmodel voor palliatieve zorg en zorg rond het levenseinde te kunnen vervullen.

GEZONDHEIDSONDERZOEK IN HET CARIBISCH GEBIED

Inzicht in de bureaucratische maatschappelijke en organisatorische cultuur kan de onderzoeker helpen om zijn weg te vinden in het uitdagende en moeizame proces van het verrichten van gezondheidsonderzoek binnen deze regio. De culturele modus operandi van hoe de zaken hier worden aangepakt, is wellicht gestoeld op de koloniale erfenis van het Caribisch gebied. Ik heb goede hoop dat mijn ervaringen en suggesties verder onderzoek naar volksgezondheid en palliatieve zorg kunnen stimuleren. Als inwoner van Trinidad en Tobago kan ik met enig vertrouwen zeggen dat de maatschappelijke en organisatorische cultuur van dit kleine land eerder conservatief, formeel en piramidaal oftewel top-down is. Dit houdt geenszins een oordeel in, maar is louter een constatering die van invloed kan zijn op het opnemen van onderzoeksprojecten. Mijn ervaring en interactie met supervisors en collega's bij de End-of-Life Care Research Group van de Vrije Universiteit Brussel was geheel anders. De hiërarchische afstand tussen senior en junior was minder uitgesproken, medewerkers spraken elkaar met de voornaam aan, maar daarnaast was ook de tweerichtingscommunicatie een belangrijk gegeven.

Hofstede (2011) beschouwt de maatschappelijke cultuur als een onbewuste aaneenschakeling van specifieke waarden, die maken dat men geneigd is om een welbepaalde gang van zaken boven een andere gang van zaken te verkiezen, en de organisatiecultuur als een vaak zichtbare perceptie van de omgeving binnen een organisatie. Mijn ervaringen zijn relevant voor een beschrijving van een formele cultuur, aangezien ik verschillende gradaties ervan heb waargenomen tijdens mijn contacten met verschillende overheidsdiensten, om hen toegang te vragen tot gegevens en toestemming te vragen om studies te mogen uitvoeren bij overheidsdiensten, bv. bij de ziekenhuisafdeling tijdens de retrospectieve mortaliteitsstudie (mortality follow-back study). Naast het aanvragen en verkrijgen van ethische goedkeuring bleek het ook nodig om brieven te schrijven die gericht waren aan de Minister van Volksgezondheid en de algemeen directeurs van de Regionale Gezondheidsautoriteit waar het ziekenhuis is gevestigd. Intentieverklaringen werden geschreven aan het hoofd van de afdeling die zich bezighield met de ‘medische dossiers’ van het ziekenhuis, gevolgd door een persoonlijke ontmoeting. Daarnaast had ik verschillende ontmoetingen met de medische en chirurgische stafhoofden, met inbegrip van hun uitvoerend assistenten. Deze specifieke omstandigheden vereisten de nodige voorbereiding en het nodige doorzettingsvermogen, al gelden deze omstandigheden wellicht niet alleen binnen het Caribisch gebied. Ondanks deze noodzakelijke formaliteiten en plichtplegingen, is het juist ook te danken aan de medewerking van de overheidsinstanties en het enthousiasme van de mensen met wie wij hebben mogen samenwerken dat deze onderzoeksprojecten konden worden uitgevoerd. De relatief beperkte beschikbaarheid van doctoraatsprogramma's, bijvoorbeeld om palliatieve zorg en zorg rond het levenseinde te onderzoeken, zou er wel eens toe kunnen bijdragen dat onderzoek als een nieuwigheid of luxe-activiteit wordt beschouwd. Dit kan op zichzelf natuurlijk al een belemmering zijn om in het Caribisch gebied onderzoek te doen.

BIO ETHIEK EN PALLIATIEVE ZORG IN HET CARAÏBEN

Zorgverleners, met name artsen, kunnen routinematig een reeks ethische problemen tegenkomen bij het verlenen van zorg aan hun patiënten, d.w.z. situaties waarin sprake is van conflicten over wat er moet worden gedaan of beslissingen waarbij concurrerende waarden een rol spelen. Bredere ethische kwesties rond palliatieve zorg en levenseindezorg kunnen de vertrouwelijkheid en bekwaamheid van de patiënt, toewijzing van middelen, wilsverklaringen, euthanasie en hulp bij zelfdoding door een arts of volmacht omvatten. Enkele daarvan komen aan de orde op de voorgaande pagina's van dit proefschrift, bijvoorbeeld kwesties met betrekking tot toegang tot palliatieve zorg, waaronder de beschikbaarheid en het effectieve gebruik van opioïden voor pijnbestrijding (hoofdstukken 2, 3, 4, 6 en 7), de autonomie van de patiënten en hun inclusie in de besluitvorming over hun zorg en behandeling, de autonomie van de patiënt en hun inclusie in de besluitvorming over hun zorg en behandeling, en het onthouden of staken van medische behandelingen inclusief kunstmatige voeding en hydratatie tijdens de laatste weken of dagen van het leven (hoofdstuk 6) en (hoofdstuk 7) behoorden tot de beschreven ethische kwesties. Het is dan ook belangrijk dat zorgaanbieders een basiskennis hebben van de reikwijdte van hun praktijk in relatie tot ethische principes en zich bewust zijn én in staat zijn om ethische kwesties, die als een norm voor kwaliteit van zorg kunnen worden beschouwd, gevoelig te beheren.

6. IMPLICATIES

AANBEVELINGEN VOOR DE PRAKTIJK

ONDERWIJS EN OPLEIDING: FORMELE ZORGVERLENERS

Onze bevindingen, (Hoofdstuk 7), suggereren dat weinig huisartsen (als primaire formele zorgverleners) een formele basisopleiding in de palliatieve geneeskunde genoten hebben en er nog minder gespecialiseerde artsen in de palliatieve geneeskunde zijn. Verdere resultaten gaven aan dat de aard van de zorgverlening verschilde tussen huisartsen met of zonder deze opleiding, omdat de artsen die opgeleid waren in de palliatieve geneeskunde meer proactief blijken in de communicatie met de patiënt, diens familie of met andere zorgverleners, en zij ook vaker opioïde medicatie gaven ter pijnbestrijding. Het vermijden van het gebruik van opioïden ter pijnbestrijding komt zowel in ontwikkelings- als ontwikkelde landen voor en kan te maken hebben met beperkte of verouderde kennis en voorlichting over het veilige en effectieve gebruik ervan. De erkenning van palliatieve geneeskunde en palliatieve zorg door medische, verpleegkundige en paramedische gezondheidsautoriteiten is nodig om de basiskennis te verbreden en verdiepen. Palliatieve zorgmodules zouden geïntegreerd moeten worden in de curricula van de basisopleiding geneeskunde en verpleegkunde. Er is ook behoefte aan meer gespecialiseerde opleidingen (en graden binnen de) geneeskunde en verpleegkunde op de drie campussen van de University of the West Indies (in Jamaica, Barbados en Trinidad en Tobago), en er moeten onderwijsindicatoren en accreditatieprogramma's worden ontwikkeld voor zorgverleners. Daarnaast is er dringend behoefte aan een nationaal of Caribisch regionaal specialistentraject voor zowel een basis- als voortgezette opleiding in palliatieve zorg voor artsen, verpleegkundigen en andere zorgverleners.

ONDERWIJS EN OPLEIDING: INFORMELE ZORGVERLENERS

Familieleden waren de belangrijkste informele zorgverleners van personen met levensbekortende of levensbedreigende aandoeningen die werden verzorgd doch gestorven zijn in een privéwoning (hoofdstuk 6) en (hoofdstuk 7). De nog onbeantwoorde zorgbehoeften van patiënten en mantelzorgers lijken universeel te zijn, en deels te wijten aan een gebrek aan sociale steun, maar ook door een gebrek aan mogelijkheden om kennis en vaardigheden te verwerven om de nodige zorg te kunnen verlenen. In het bijzonder voor de thuissituatie kan de gemeenschap zelf het initiatief nemen om deze tekortkoming aan te pakken door als informele zorgverleners via sociale media actief te communiceren over palliatieve zorg en zorg aan het einde van het leven, en waar ze steungroepen kunnen organiseren om hun eigen vaardigheden in de palliatieve zorg verder te ontwikkelen. Deze gemeenschapsinitiatieven moeten worden ondersteund met middelen van gouvernementele en niet-gouvernementele aard (d.w.z. samenwerkingsverbanden) om standaardisatie van informatie en vaardigheden mogelijk te maken, zodat bijv. artsen, verpleegkundigen of rouwbegeleiders deze zorgverleners kunnen begeleiden tijdens trainingssessies.

Uit onderzoek blijkt dat vrijwilligers een positieve bijdrage leveren aan de doelstellingen van de palliatieve zorg. De betrokkenheid van vrijwilligers kan het dienstenaanbod verder uitbreiden, vaak tot buiten de reguliere openingstijden van de formele zorgverlening. Zij kunnen ook binnen hun eigen gemeenschap aan de slag gaan en op die manier direct bij de patiënten en hun familie thuis of in een centrale gemeenschapssetting gaan werken. De activiteiten van vrijwilligers kunnen bestaan uit praktische patiëntenzorg zoals het regelen van voeding en verzorging voor patiënten, of het regelen van vervoer voor patiënten en hun familie van en naar zorgafspraken, het bieden van sociale ondersteuning of gezelschap, of het bieden van emotionele ondersteuning wanneer taboe- of erg gevoelige onderwerpen worden besproken, alsook het aanbieden van rouwbegeleiding voor familieleden.

Het is echter mogelijk dat vrijwilligerswerk in onze gemeenschappen in Trinidad en Tobago een sluimerend bestaan leidt. Afgezien van religieuze geloofsovertuigingen die reeds vrijwilligersgroepen organiseren voor hun verschillende activiteiten en projecten, is vrijwilligerswerk niet vanzelfsprekend. Uit een enquête die in 2016 door een vrijwilligersorganisatie in Trinidad en Tobago werd gehouden, bleek dat de populairste activiteiten voor hun vrijwilligers eerder draaiden om mentorschap en het geven van bijles, bewustmaking van sociale kwesties en het engagement voor milieubehoud. De uitdagingen liggen niet alleen in het identificeren van mogelijke vrijwilligers om deel te nemen aan palliatieve zorg en zorg rond het levenseinde in hun gemeenschap (activiteiten waarmee ze misschien niet vertrouwd zijn), hoe hun interesse en motivatie om vrijwilligerswerk te blijven doen, op peil te houden, maar ook om cliënten (patiënten en hun families) te overtuigen om hun deuren open te stellen voor een groot aantal vrijwilligers. Dit zijn misschien uitdagingen voor de meeste vrijwilligersgroepen of -organisaties, waardoor het vinden van het benodigde aantal vrijwilligers voor gemeenschapsdiensten in de palliatieve zorg op korte termijn niet haalbaar kan zijn. Een mogelijk alternatief zou zijn om de aandacht te richten op de rol van familie en vrienden en netwerken tussen hen te vormen, aangezien zij waarschijnlijk al betrokken zijn bij het concept van "het geven van hun tijd" ten dienste van de palliatieve zorg.

BELEIDSAANBEVELINGEN

NATIONAAL BELEID VOOR PALLIATIEVE ZORG

Er dient een nationaal beleid voor palliatieve zorg te worden ontwikkeld en geïmplementeerd dat voldoende ruimte biedt aan initiatieven van maatschappelijke organisaties en lokale overheden. De Wereldgezondheidsorganisatie en andere internationale pleitbezorgers voor palliatieve zorg hebben uitvoerig advies gegeven over de noodzaak van een nationaal gezondheidsbeleid in landen waar palliatieve zorg onderontwikkeld is. Trinidad en Tobago en vele andere Caribische landen zijn ondertekenaars van de resolutie van de 67ste Wereldgezondheidsvergadering (WHA) die in 2014 in Zwitserland werd gehouden. De ministers van Volksgezondheid kwamen daar overeen om nationale actieplannen te faciliteren die de belemmeringen voor de beschikbaarheid van en toegang tot palliatieve zorg zullen verminderen. Het doel van een nationaal beleid is om palliatieve zorg en zorg aan het levenseinde te integreren in alle nationale gezondheidsplannen en in een algemeen gezondheidsbeleid, bijvoorbeeld op het gebied van kanker, niet-overdraagbare ziekten, infectieziekten (hiv/aids en tuberculose) en kindergeneeskunde, en om nationale normen voor palliatieve zorg te ontwikkelen.

OPSCHALING VAN PALLIATIEVE ZORG

De huidige dienstverlening moet worden opgeschaald en er moet een volksgezondheidsmodel voor palliatieve zorg worden aangenomen. Uit onze onderzoeken naar de plaats van overlijden (Hoofdstuk 3) en (Hoofdstuk 4) blijkt dat ongeveer dertig procent van de sterfgevallen op nationaal niveau plaatsvindt in een particuliere woning. Dit suggereert dat er grote behoefte is aan thuiszorg, maar deze diensten moeten gecoördineerd worden om zorgcontinuïteit mogelijk te maken. De capaciteit is reeds aanwezig om palliatieve zorgdiensten in gemeenschappen uit te breiden. Afgezien van de grote overheidsziekenhuizen zijn er meer dan 100 gezondheidscentra en gezondheidsfaciliteiten (een uitgebreid gezondheidscentrum dat aanvullende diensten aanbiedt) die voorzien in het aanbod van eerstelijnsgezondheidszorg. Een praktische aanzet zou erin kunnen bestaan om palliatieve zorg op te nemen als onderdeel van de eerstelijnsgezondheidszorg in strategisch (afhankelijk van de geografie of bevolkingsdichtheid) gelegen gezondheidscentra. Dit kan gefaseerd gebeuren om mettertijd een nationaal netwerk uit te bouwen. Het betrekken van huisartsen is hierbij cruciaal aangezien onze mortaliteitsstudie (Hoofdstuk 6) en (Hoofdstuk 7) heeft aangetoond dat zij de belangrijkste formele palliatieve zorgverleners zijn en een sleutelrol vervullen qua medische zorgverlening. Daarnaast kan een multidisciplinair kernteam voor palliatieve zorg worden opgericht in elk van de vijf regionale gezondheidsautoriteiten om ondersteuning te bieden aan huisartsen in de gemeenschap.

INVESTEREN IN ONDERWIJS EN BEWUSTWORDING

Uit onze studie (Hoofdstuk 7) blijkt dat artsen met een formele opleiding in de palliatieve zorg andere beslissingen namen over medische behandelingen aan het levenseinde dan degenen die geen dergelijke opleiding achter de kiezen hadden. Ook uit informatie van (hoofdstuk 6) blijkt dat informele zorgverleners, waaronder familieleden, de belangrijkste zorgverleners vormen in de thuissituatie, maar het is nog gissen naar hun capaciteiten om de juiste zorg te verlenen. Waarschijnlijk hebben de meesten van hen hiertoe geen specifieke opleiding genoten. Om een succesvol initiatief te ontwikkelen, is het daarom essentieel dat politici, sociale activisten, professionals in de gezondheidszorg en het grote publiek bewust worden gemaakt van de huidige situatie rond het sterven aan levensbekortende en levensbedreigende aandoeningen, maar ook van de voordelen van palliatieve zorg voor de patiënt, familieleden en zorgverleners.

INVESTEREN IN PALLIATIEVE ZORGDIENSTEN MET FINANCIERING

Er zijn aanwijzingen dat de kosten voor gezondheidszorg kunnen worden verlaagd en dat de kwaliteit van de resultaten voor de patiënt en het gezin kan worden verbeterd door vroegtijdige integratie van palliatieve zorg bij de behandeling van patiënten met levensbeperkende of levensbedreigende aandoeningen. Zoals aanbevolen door de

Wereldgezondheidsorganisatie, kan het Ministerie van Volksgezondheid toezicht houden op de financieringsmechanismen die nodig zijn om palliatieve zorg te ontwikkelen. Dit kan een financiële subgroep zijn die bestaat uit palliatieve zorgverleners, gezondheidseconomen, gezondheidsbeheerders van elke regionale gezondheidsautoriteit en sociale dienstverleners. De overheid zou de bestaande financierings- en dienstverleningsmodellen moeten herzien om de kosten van het verlenen van palliatieve zorg in de verschillende omgevingen te bepalen.

UPDATE EN WIJZIG E DANGEROUS DRUGS ACT

De "Dangerous Drugs Act" in Trinidad en Tobago is voor het laatst bijgewerkt in 2007. Het doel van dit document is om het gebruik van verdovende middelen te beperken, maar bij uitbreiding is het medisch gebruik van opioïden voor pijnbestrijding ook beperkt. Bevindingen uit onze scoping review (Hoofdstuk 2) en onze mortaliteits follow-back studie (Hoofdstuk 6 en Hoofdstuk 7), wezen wel op een laag gebruik van en toegang tot opioïden voor medische doeleinden, aangezien het medische opioïdengebruik in 2013 1–10 mg morfine-equivalenten/hoofd/jaar was. Er kan een subgroep van het drugsbeleid van de overheid worden gevormd om het medisch gebruik van opioïden voor pijnbestrijding te beoordelen. Tot de leden van de subgroep behoren geneesmiddelenregulatoren, farmacologen en apothekers, wetshandhavingsinstanties en indien nodig nationale en internationale deskundigen op het gebied van pijn en palliatieve zorg, en kunnen er vertegenwoordigers van de International Narcotics Control Board (INCB) zijn. Het doel hier omvat het herbekijken en indien nodig een herziening van de wet- en regelgeving op het gebied van verdovende middelen die de invoer, registratie, opslag, distributie, verstrekking, verantwoording, prijsstelling en voorschrijfpraktijken regelen om de adequate beschikbaarheid, toegankelijkheid en betaalbaarheid van essentiële geneesmiddelen voor palliatieve zorg te waarborgen, waaronder orale morfine.

INVESTEREN IN DE KWALITEIT VAN DE DOODCERTIFICERING EN VAN DOODCERTIFICERINGSGEGEVENS

Overlijdensakten kunnen een nuttig onderzoeksinstrument zijn. Gegevens uit onze studies (hoofdstukken 3, 4, 6 en 7) maakten melding van enkele tekortkomingen van de overlijdensakten die werden gebruikt om een overlijden te registreren. We hebben inconsistentie waargenomen in de kwaliteit van de voltooiing en het ontbreken van noodzakelijke informatie die het gebruik ervan als een nuttige bron van routinegegevens bij het monitoren van kwaliteitsvolle zorg bij levenseinde beperkt. Andere sociaal-demografische informatie die momenteel niet op overlijdensakten staat, maar die nuttig kan zijn om vast te leggen en te controleren, zijn onder meer de burgerlijke staat, de inkomensgroep, het opleidingsniveau, de woonsituatie en het niveau van verstedelijking van de gebruikelijke woonplaats van de overledene. Deze informatie wordt beschouwd als betrouwbare voorspellers voor de plaats van overlijden, en er moeten wijzigingen worden aangebracht om deze variabelen aan overlijdensakten toe te voegen. Bijkomende informatie zoals de nationaliteit (geboorteland), of woonkenmerken zoals de gemeente van het overlijden en de woonplaats, of kenmerken van het gezondheidszorgsysteem zoals het aantal ziekenhuisbedden per 1.000 inwoners, kan ook nuttig zijn om op te nemen. De plaats van overlijden is beperkt tot vier categorieën, en groepeert zeer uiteenlopende plaatsen zoals verpleeghuizen, privéziekenhuizen, hospice en bejaardenhuizen. Hierdoor kan de evaluatie van het beleid rond zorg bij levenseinde, waarbij overlijdensakten als gegevensbron worden gebruikt, belemmerd worden. Relevante overheidsinstanties en medische scholen zouden moeten investeren in de kwaliteit van overlijdenscertificering door tools te ontwikkelen of de vaardigheden van artsen te vergroten en te streven naar nauwkeurigheid en uniformiteit.

AANBEVELINGEN VOOR ONDERZOEK

PLAATS VAN OVERLIJDEN

Met de meest recente sterftegegevens die beschikbaar zijn, stellen we voor om verder onderzoek naar de plaats van overlijden op bevolkingsniveau uit te voeren in landen met weinig middelen, inclusief trends in de plaats van overlijden in relatie tot de palliatieve zorg en zorg bij levenseinde, rekening houdend met verschuivingen in de onderliggende doodsoorzaak, leeftijd en geslacht van de overleden populaties. Kwalitatieve studies kunnen worden overwogen om een beter begrip te krijgen van hetgeen de keuzes van de plaats van overlijden beïnvloedt, inclusief zorgdiensten, veranderingen in sociale middelen, attitudes, overtuigingen en voorkeuren. De voorkeursplaats van overlijden of zorg is onbekend en een begrip van een dergelijke voorkeur zou gunstig zijn voor beleidsmakers en overheidsfunctionarissen om de nodige middelen en diensten toe te wijzen. In Trinidad en Tobago vond een meerderheid van de sterfgevallen die wijzen op een behoefte aan palliatieve zorg plaats in een overheidsziekenhuis (hoofdstuk 3 en hoofdstuk 4), Zowel kwantitatieve als kwalitatieve studies moeten worden uitgevoerd om de kwaliteit van de ontvangen zorg te evalueren en te begrijpen (door patiënten) en geleverd (door zorgverleners) in deze setting. Gezien het belang van informele palliatieve zorg, zoals aangegeven door onze bevindingen (hoofdstuk 6), moeten toekomstige studies zich ook richten op de behoeften en ervaringen van zorgverleners, met name in de privé-thuissituatie. Longitudinale studies die meer beslaan dan de periode vlak voor het overlijden kunnen ook worden overwogen.

KOSTIMPLICATIES VAN HET VERLENEN VAN PALLIATIEVE ZORG EN BEËINDIGING VAN DE LEVENSDUUR

Door de huidige trend van de vergrijzende bevolking en veel voorkomende chronische ziekten, moet de behoefte aan palliatieve zorg in verschillende settings worden beoordeeld. De huidige diensten moeten systematisch worden geëvalueerd om een beter inzicht te krijgen in de kosten (bijv. economische en personele middelen) van het verlenen van palliatieve zorg, en de onmiddellijk te betalen kosten voor degenen die de diensten gebruiken. Tegelijkertijd moet er een evaluatie plaatsvinden van de zorg die wordt verleend in overheidsziekenhuizen (die kan worden erkend als palliatieve zorg en zorg bij levenseinde). Gegevens kunnen worden verzoend (reconciled) om beter te begrijpen waar de vraag naar middelen is om de benodigde services efficiënt op te bouwen en toe te wijzen.

INTERVENTIESTUDIES

Er zijn interventies nodig die gericht zijn op enkele van de specifieke behoeften rond palliatieve zorg en zorg bij levenseinde in Trinidad en Tobago, bijvoorbeeld trainings- en ondersteuningsprogramma's voor familie en zorgverleners, en voorlichtingsprogramma's over de dood voor het grote publiek. Dit vereist twee soorten onderzoek. Ten eerste uitgebreid onderzoek op het gebied van volksgezondheid (gezondheidsbevordering) gericht op de ontwikkeling van nieuwe of aangepaste interventies, waarbij het noodzakelijke implementatiewetenschappelijke perspectief wordt toegepast en waarbij de verschillende relevante belanghebbenden worden betrokken, waaronder: gemeenschappen en buurten, maatschappelijke organisaties, gezondheids- en aanverwante zorgverleners en overheidsinstanties. Ten tweede, onderzoek dat experimentele ontwerpen toepast die het mogelijk maken conclusies te trekken over de causaliteit van interventies en hun werkingsmechanismen op relevante uitkomsten. Dit soort onderzoek zou een belangrijke stap zijn in de richting van een meer evidence-based zorgprogramma en planning bij levenseinde.

8.9 CONCLUDING REMARKS

This document concerns empirical evidence on palliative and end-of-life care in Trinidad and Tobago. It illustrates not only the need for palliative care that can exist in a society with an ageing population and high prevalence of chronic life-limiting medical conditions, but also that much more needs to and can be done by society to appropriately respond to the needs. The situation in this small resource-poor Caribbean country is probably not a unique one as the circumstances and challenges we uncovered may be similar to those of other Caribbean nations, and other developing and resource-poor countries and regions. I am hopeful that the research methods used in this thesis might offer insight to other researchers, and the implications and recommendations we advocated will be considered by policy makers as a way forward toward the integration into the health system and further development of palliative care. This concludes this document, a thesis on palliative and end-of-life care in a small English-speaking Caribbean country, the case of Trinidad and Tobago.

CURRICULUM VITAE

Nicholas is a critical care registered nurse (RN) with a master’s degree in public health from St. George’s University School of Medicine, St. George’s Grenada. He worked as a Caribbean regional coordinator for the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) programme. Nicholas joined the End-of-Life Care Research Group at Vrije Universiteit Brussel in 2015 as a junior researcher, the first from the Caribbean and was supervised by Prof. dr. Joachim Cohen, Prof. dr. Kenneth Chambaere, Prof. dr. Luc Deliens, and Prof. dr. Cheryl Cox Macpherson from St. George’s University. His involvement with the Caribbean Palliative Care Study explored the use of available administrative data that can be used for research purposes particularly in countries or regions that are resource-poor and lack infrastructure for doing robust research. Other project strategies included the use of observational and cross-sectional methodologies for generating new data in resource-poor contexts.

APPENDICES

CHAPTER 2

Revista Panamericana de Salud Pública / Pan American Journal of Public Health

Supplementary material to manuscript: Jennings N, Chambaere K, Macpherson CC, Deliens L, Cohen J. Main themes, barriers, and solutions to palliative and end-of-life care in the English-speaking Caribbean: a scoping review. Rev Panam Salud Publica. 2018;42:e15. doi: 10.26633/RPSP.2018.15

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	• 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). • 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). • 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). • 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). • Cancer patients underreport pain, believing that complaining distracts	• 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). • 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). • 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). • 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;	• 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). • 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). • Health care practitioners can improve their ability to communicate with patients, families, and caregivers about realistic disease trajectories and viable options (24, 32). • The development of multidisciplinary, community-based palliative care programs comprised of physicians, nurses, social workers, and religious and volunteer communities are also necessary (22,

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

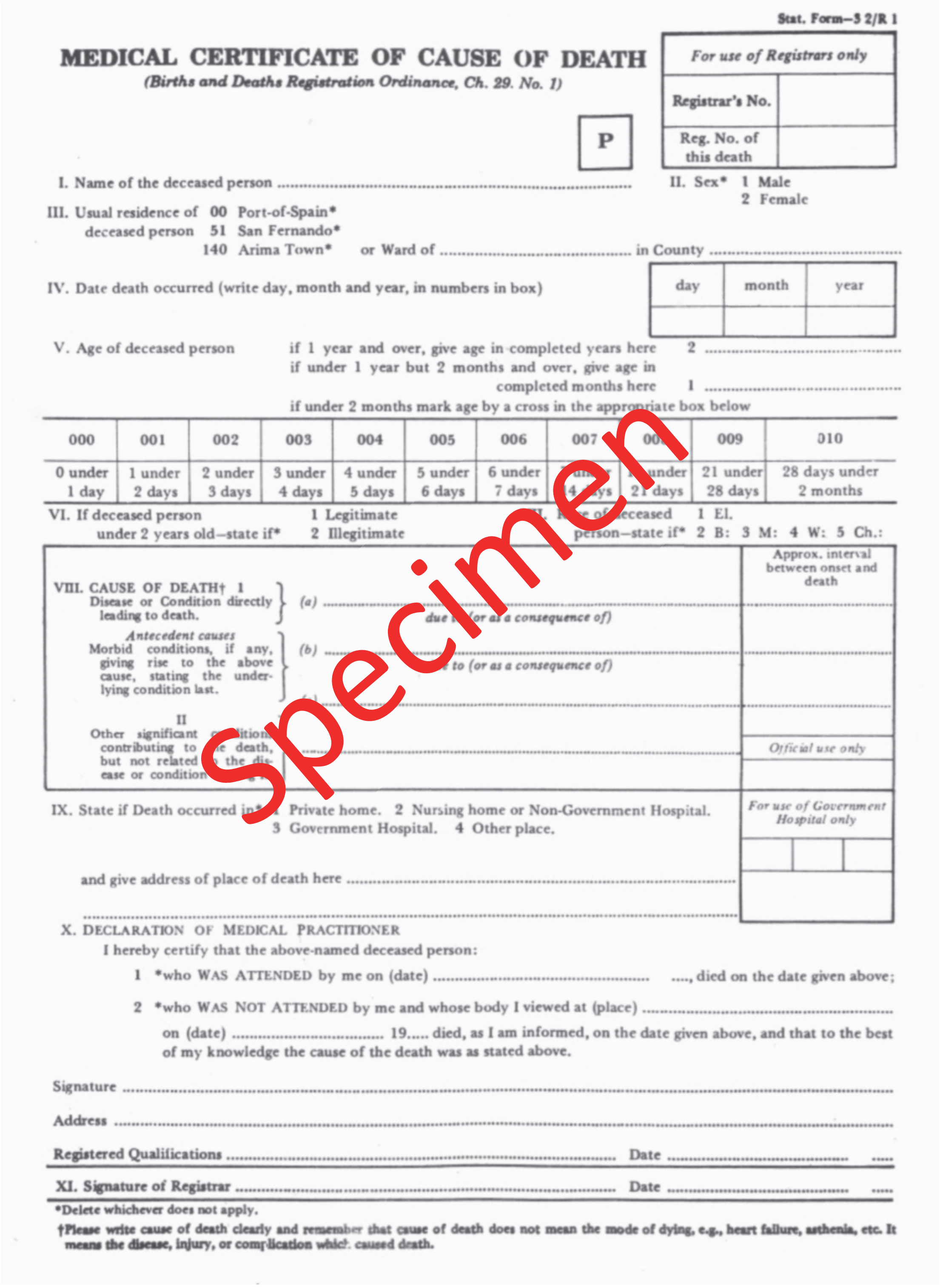
	palliative care capacity	countries by Lynch et al. (20). Of the six categories, English-speaking Caribbean nations are in groups 1, 2, and 3a. The Group 1 countries (with no known hospice-palliative care activity) are Antigua and Barbuda, Grenada, Saint Kitts and Nevis, and Saint Vincent and the Grenadines. 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).	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).
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.	• 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.

Source: Prepared by the authors using study data.

CHAPTER 3

Appendix 1. Sample of medical certificate of cause of death, Trinidad and Tobago 2010



Stat. Form—3 2/R 1

MEDICAL CERTIFICATE OF CAUSE OF DEATH

(Births and Deaths Registration Ordinance, Ch. 29. No. 1)

P

For use of Registrars only	
Registrar's No.	
Reg. No. of this death	

I. Name of the deceased person ....

II. Sex* 1 Male
2 Female

III. Usual residence of deceased person
00 Port-of-Spain*
51 San Fernando*
140 Arima Town* or Ward of .... in County ....

IV. Date death occurred (write day, month and year, in numbers in box)

day	month	year

V. Age of deceased person
if 1 year and over, give age in completed years here 2 ....
if under 1 year but 2 months and over, give age in completed months here 1 ....
if under 2 months mark age by a cross in the appropriate box below

000	001	002	003	004	005	006	007	008	009	010
0 under 1 day	1 under 2 days	2 under 3 days	3 under 4 days	4 under 5 days	5 under 6 days	6 under 7 days	7 under 14 days	14 under 21 days	21 under 28 days	28 days under 2 months

VI. If deceased person under 2 years old—state if* 1 Legitimate 2 Illegitimate

VII. Race of deceased person—state if* 1 El. 2 B: 3 M: 4 W: 5 Ch.:

VIII. CAUSE OF DEATH† | Approx. interval between onset and death

1
Disease or Condition directly leading to death. (a) ....
due to (or as a consequence of)

Antecedent causes
Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last. (b) ....
due to (or as a consequence of)
(c) ....

II
Other significant conditions contributing to the death, but not related to the disease or condition causing it ....

Official use only

IX. State if Death occurred in* 1 Private home. 2 Nursing home or Non-Government Hospital.
3 Government Hospital. 4 Other place.

For use of Government Hospital only

and give address of place of death here ....
....

X. DECLARATION OF MEDICAL PRACTITIONER

I hereby certify that the above-named deceased person:

1 *who WAS ATTENDED by me on (date) ...., died on the date given above;

2 *who WAS NOT ATTENDED by me and whose body I viewed at (place) ....
on (date) .... 19..... died, as I am informed, on the date given above, and that to the best of my knowledge the cause of the death was as stated above.

Signature ....

Address ....

Registered Qualifications .... Date ....

XI. Signature of Registrar .... Date ....

*Delete whichever does not apply.

†Please write cause of death clearly and remember that cause of death does not mean the mode of dying, e.g., heart failure, asthenia, etc. It means the disease, injury, or complication which caused death.

Appendix 2. Distribution of deaths (2010) by Regional Health Authority (RHA)

Regional Health Authority	# of deaths per RHA (%)
North-West	2706 (26.8)
North-Central	2515 (24.9)
South-West	3425 (33.9)
Eastern	1074 (10.6)
Tobago	375 (3.7)

Prepared by authors using study data.

Supplemental table 2. Logistic regression model with the continuous variable 'number of hospital beds per 10 deaths' within an RHA, controlling for sex, age, cause of death and urbanisation; home deaths and hospital deaths are the independent variables.

	home deaths vs elsewhere		government hospital deaths vs elsewhere	
Characteristics	**OR**	**CI (95%)**	**OR**	**CI (95%)**
Sex				
Male	–	–	0.87	0.80 – 0.94
Female	1	1	1	1
Age				
0 – 17	0.30	0.20 – 0.47	2.67	2.03 – 3.49
18 – 69	1	1	1	1
70 – 89	1.89	1.72 – 2.08	0.66	0.60 – 0.72
90 – highest	3.63	3.08 – 4.27	0.25	0.21 – 0.30
Cause of death				
Malignancies	0.84	0.73 – 0.97	–	–
Diseases of the nervous system	1.44	1.08 – 1.93	0.49	0.37 – 0.66
Diabetes mellitus	–	–	–	–
Cardiovascular disease	1	1	1	1
Cerebrovascular disease	0.61	0.51 – 0.72	1.46	1.25 – 1.71
Respiratory disease	0.73	0.59 – 0.91	1.27	1.04 – 1.55
Other	0.50	0.43 – 0.56	–	–
Number of hospital beds per 10 deaths within an RHA (continuous)	0.99	0.86-1.14	1.12	0.98-1.27
Urbanisation				
Urban	1	1	1	1
Semi-urban	–	–	–	–
Rural	1.52	1.38 – 1.68	0.83	0.76 – 0.91

Logistic regression controlling simultaneously for sex, age, cause of death, 'number of hospital beds per 10 deaths' within an RHA and urbanisation
1 = reference variable

Supplemental table 3. Logistic regression model with the variable 'race/ethnicity' as an independent variable, controlling for age, sex and cause of death; home vs hospital deaths.

	home deaths vs elsewhere		**government hospital deaths vs elsewhere**	
Characteristics	**OR**	**CI (95%)**	**OR**	**CI (95%)**
Sex				
Male	–	–	–	–
Female	1	1	1	1
Age				
0 – 17	0.21	0.09 – 0.49	2.90	1.70 – 4.93
18 – 69	1	1	1	1
70 – 89	2.00	1.71 – 2.34	0.54	0.47 – 0.63
90 – highest	3.84	2.93 – 5.02	0.21	0.16 – 0.27
Cause of death				
Malignancies	–	–	–	–
Diseases of the nervous system	1.66	1.02 – 2.70	0.50	0.31 – 0.81
Diabetes mellitus	–	–	–	–
Cardiovascular disease	1	1	1	1
Cerebrovascular disease	0.56	0.43 – 0.73	1.58	1.23 – 2.03
Respiratory disease	–	–	–	–
Other	0.40	0.32 – 0.50	1.78	1.46 – 2.16
Race/ethnicity				
East Indian	–	–	2.32	1.14 – 4.71
Black	0.51	0.27 – 0.98	3.33	1.64 – 6.74
Mixed	–	–	–	–
White	1	1	1	1
Chinese	–	–	–	–

Logistic regression controlling simultaneously for sex, age, cause of death, and race/ethnicity
1 = reference variable

CHAPTER 4

Appendix 1. Place of death proportions by year, observed and standardised in Trinidad and Tobago, 1999-2010

Years	Private home obs (%)	Government hospital obs (%)	Nursing home/ private hospital obs (%)	Other obs (%)	Private home std (%)	Government hospital std (%)	Nursing home/ private hospital std (%)	Other std (%)
1999	38.7	48.9	7.1	5.3	38.7	48.9	7.1	5.3
2000	38.3	49.3	7.6	4.8	39.1	48.5	7.8	4.6
2001	37.6	50.2	6.0	6.2	38.0	49.9	6.1	5.9
2002	37.3	50.0	5.3	7.4	37.6	50.0	5.3	7.1
2003	37.6	47.3	6.5	8.6	37.6	47.4	6.7	8.4
2004	35.4	51.2	5.6	7.8	35.3	51.6	5.6	7.5
2005	33.7	51.7	6.3	8.3	33.6	52.1	6.4	7.9
2006	32.5	52.7	6.3	8.5	32.2	53.5	6.3	8.0
2007	30.5	53.2	7.2	9.0	30.3	54.1	7.1	8.5
2008	30.1	53.2	7.6	9.1	30.1	54.2	7.6	8.1
2009	28.5	56.4	6.6	8.5	28.7	57.1	6.6	7.7
2010	29.7	55.4	5.9	8.9	29.2	56.6	5.8	8.4

Abbreviations: obs – observed, std – standardised. Population distributions were standardized using the 1999 population as the standard population for age, sex and cause of death

CHAPTER 5

Appendix 1: Validated questionnaire

Confidential Enquiry Into Care And Medical Decision Making At End-Of-Life In Trinidad And Tobago: 2018

Dear colleague – Quality medical care at the end of life is an increasing challenge and there is little to no scientific data on end-of-life care in Trinidad and Tobago. In order to generate objective scientific knowledge, knowledge of your experiences in practice is indispensable.

Objective – To **ANONYMOUSLY** survey practicing physicians about their experiences in patient care and medical decision making at the end of life.

What is asked of you? – Please try to recall as carefully as possible the patient that is referred to in the accompanying letter, where you were the ***ATTENDING PHYSICIAN*** (if necessary, using the patient's file or medical records) and complete this questionnaire as accurately as possible. ***Please read the accompanying letter to this questionnaire prior to completing the questionnaire.***

Research partners:
- *St George's University School of Medicine, Grenada (SGU)*
- *End-of-Life Care Research Group of the Vrije Universiteit Brussel (VUB) and Ghent University, Belgium.*
- *The Central Statistical Office (CSO) of Trinidad and Tobago*
- *The Trinidad and Tobago Medical Association (T&TMA) and*
- *The North Central Regional Health Authority (NCRHA)*
- *Nicholas Jennings is the primary researcher who is a national and resident of Trinidad and Tobago*

THERE ARE 26 QUESTIONS IN THIS QUESTIONNAIRE
COMPLETING THE QUESTIONNAIRE WILL TAKE YOU ABOUT 2-12 MINUTES

PLEASE TICK ☑ THE BOX OR BOXES TO INDICATE YOUR RESPONSES

General

1	**Was this death sudden and totally unexpected?**	☐ Yes: ***go to Question 21 on page 4*** ☐ No
2	**When was your first contact with the patient?**	☐ At the time of or after death: ***go to Question 21 on page 4*** ☐ Before death, (please indicate length of time) . . . .

Care and Treatment concerning this patient prior to his/her death

3	**Of the following, which treatment goal was given priority in the <u>last 7 days of life</u>?** *(Choose only one answer, i.e. the <u>main</u> treatment goal)*	☐ Cure ☐ Prolonging life ☐ Maintenance of function ☐ Maximization of comfort ☐ No overall treatment goals were set ☐ I have no information regarding the last week of life
4	**Which of the following treatment(s) were given in the <u>last 30 days of life</u>?** (*multiple answers possible*)	☐ Analgesics ☐ Antibiotics ☐ Artificial hydration (intravenous line, subcutaneous) ☐ Artificial nutrition (parenteral nutrition, P.E.G. tube) ☐ Artificial ventilation (intubation or BPAP) ☐ Chemotherapy or other cancer therapy ☐ Cardiopulmonary resuscitation (CPR) ☐ Dialysis ☐ Surgery ☐ Transfusion of blood products ☐ I have no information regarding the last 30 days of life ☐ Other, (please specify) . . . .
5	**In which of the following places did the patient receive care in the <u>last 30 days of life</u>?** (*multiple answers possible*)	☐ At home ☐ Ward in hospital ☐ Intensive care unit in the hospital ☐ Hospice/palliative care unit ☐ Geriatric home/Nursing home
6	**Which of the following caregivers, besides yourself, were actively involved in the care for the patient in the <u>last 30 days of life</u>?** (*multiple answers possible*)	☐ Specialist ☐ Nurse ☐ Psychiatrist/psychologist ☐ Family member ☐ Friend ☐ I don't know ☐ Volunteer ☐ Social worker ☐ Religious/moral counsellor ☐ Religious community member ☐ No one
7	**Who, <u>to your knowledge</u>, was present when the patient died?** (*multiple answers possible*)	☐ You or another physician ☐ Nurse ☐ Geriatric home staff ☐ Family member(s) ☐ Other, (please specify) . . . . ☐ Friend(s) ☐ Religious counsellor ☐ No one, patient died alone
8	**What was the patient's preferred place of death?**	☐ At home ☐ Hospital ☐ Other, (please specify) . . . . ☐ Geriatric home/Nursing home ☐ I don't know
9	**Did this patient receive any *<u>*palliative care</u>* (at home, in a hospital or elsewhere)?** (*multiple answers possible*)	☐ Yes, by a palliative care service ☐ Yes, by a family member ☐ Yes, by a social worker ☐ Yes, by myself and/or other clinician ☐ Yes, by a psychologist ☐ No: ***go to Question 11***
10	**When did the patient first receive *<u>*palliative care</u>* before his/her death?**	☐ 1-7 days: ***go to Question 12*** ☐ 1-4 weeks: ***go to Question 12*** ☐ 1-3 months: ***go to Question 12*** ☐ 3-6 months: ***go to Question 12*** ☐ More than 6 months: ***go to Question 12*** ☐ I don't know: ***go to Question 12***
11	**For which reason(s) was *<u>*palliative care</u>* not initiated?** (*multiple answers possible*)	☐ Unaware of how to access palliative care services in my region ☐ I didn't think the patient needed palliative care ☐ A person or service qualified in palliative care, was not available ☐ There was insufficient time to initiate palliative care ☐ To not take away hope from the patient or the family ☐ Financial constraints of the patient or family ☐ Patient did not want it ☐ Family did not want it ☐ Other, (please specify) . . . .

**** By Palliative Care we mean "Care that helps people live their life as fully and as comfortably as possible when living with a terminal illness. It identifies and treats symptoms which may be physical, emotional, spiritual or social."***[28]

Medical practice

12	**Please indicate whether you prescribed or administered any of the following drugs to treat or alleviate symptoms this patient had in the <u>last 7 days of life</u>?** (*multiple answers possible*)	☐ No drugs were used to alleviate symptoms: ***go to Question 14*** ☐ Morphine or other opioid ☐ Diazepam or other benzodiazepine ☐ Dopamine or other vasopressors ☐ Chlorpromazine or other phenothiazines ☐ Laxative ☐ Antiemetic ☐ Other drug (please specify) . . . .
13	**In your opinion, could the administration of these drugs have influenced the timing of death?**	☐ No influence on timing of death: ***go to Question 15*** ☐ Yes, possibly delayed the timing of death: ***go to Question 15*** ☐ Yes, possibly brought forward the timing of death: ***go to Question 15*** ☐ Yes, certainly brought forward the timing of death: ***go to Question 15***
14	**Why were no drugs used to alleviate symptoms?** (*multiple answers possible*)	☐ Patient had no significant symptoms ☐ Drugs were not available ☐ Financial constraints of the patient or family ☐ To avoid drug side-effects (life-shortening or addiction) ☐ Patient refused ☐ Family refused ☐ Other, (please specify) . . . .
15	**Did you withhold and/or withdraw any of the following potentially life-prolonging treatment(s)?**	☐ No: ***go to Question 16*** ☐ Yes: if yes, **Please tick the appropriate box(s)** *<u>multiple answers possible</u>*

	Antibiotics	Artificial hydration (intravenous line, subcutaneous)	Artificial nutrition (parenteral nutrition, P.E.G. tube)	Artificial ventilation (intubation or BPAP)	Chemo-therapy or other cancer therapy	Dialysis	Transfusion of blood products	Cardio-pulmonary resuscitation (CPR)	Surgery
Withheld	☐	☐	☐	☐	☐	☐	☐	☐	☐
Withdrawn	☐	☐	☐	☐	☐	☐	☐		

16	**In your opinion, could the withholding and/or withdrawing of treatments have influenced the timing of death?**	☐ No influence on timing of death ☐ Yes, possibly brought forward the timing of death ☐ Yes, certainly brought forward the timing of death

Decision-making

17	**Did you discuss with the patient the various options related to end-of-life treatments?** (*multiple answers possible*)	☐ Yes, about withholding treatment(s) ***go to Question 19*** ☐ Yes, about withdrawing treatment(s) ***go to Question 19*** ☐ Yes, about giving drug(s) to alleviate pain and/or symptoms ***go to Question 19*** ☐ No, no discussion: ***go to Question 18***
18	**Why was there no discussion with the patient about the various options related to end-of-life treatments?** (*multiple answers possible*)	☐ Patient was unconscious: ***go to Question 19*** ☐ Patient had significant cognitive impairment: ***go to Question 19*** ☐ Patient had a psychiatric disorder: ***go to Question 19*** ☐ Other (please specify) . . . .
19	**With whom, of the following, did you discuss the end-of-life treatment options for this patient?** (*multiple answers possible*)	☐ With your medical colleague/s ☐ Nursing staff ☐ Another caregiver ☐ The patient's partner or relatives ☐ Other person (please specify) . . . .
20	**As far as you know, did the patient ever express a wish for the end of life to be hastened?**	☐ Yes, explicitly ☐ Yes, but not explicitly ☐ No ☐ I don't know

Information regarding yourself as a physician

21	**What is your gender?**	☐ Male ☐ Female
22	**How long have you practiced as a physician?**	☐ under 5 years ☐ 5 to 10 years ☐ 11 to 15 years ☐ 16 to 20 years ☐ over 20 years
23	**Have you ever had any formal training in palliative care?** (*multiple answers possible*)	☐ No ☐ Yes, as part of my medical degree ☐ Yes, postgraduate education programme ☐ Other training, (please specify) . . . .
24	**Do you consider you have enough expertise to communicate adequately with patients at the end of life?** (*multiple answers possible*)	☐ No ☐ Yes, through experience/informal training ☐ Yes, through formal training
25	**Do you consider you have enough expertise to communicate adequately with family of patients at the end of life?** (*multiple answers possible*)	☐ No ☐ Yes, through experience/informal training ☐ Yes, through formal training
26	**Do you feel sufficiently supported, by the current protocols of care in Trinidad and Tobago, with your preferred management and decision-making at the end of life for your patient?**	☐ No ☐ Yes If you wish, please elaborate your response choice here. . . . .

Thank you for your valued participation. To ensure anonymity of your answers you will need to:

(1) Place the completed questionnaire in the reply-paid envelope, seal it and post it as soon as possible. (Contact TTPOST; email address: *pickup@ttpost*.net or call: 669-5361 EXT 519 or 527 to collect the package) and please provide the following information: Address, Contact Name or Department & Phone Number

- **It will be received by an independent person in a different location and kept separate.**
- **It will not be possible for the researchers or anyone else to use your replies to discover your identity or the identity of the patient on whose care you have reported.**

It is of course impossible to do justice to all the finer nuances of palliative and end-of-life care in a short questionnaire. If some of your answers require further clarification, please write in the space below.

. . . .

. . . .

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Supplemental 1. Interview guide

END-OF-LIFE CARE
RESEARCH GROUP
UNIVERSITEIT GENT VUB

Trinidad & Tobago
Medical Association

St. George's University
THINK BEYOND
Grenada, West Indies

Questionnaire Validation

ID number:

Date:

Questionnaire version: ☐ **Phase 1** ☐ **Phase 2**

Participant: ☐ **General practitioner** ☐ **Hospital specialist**

General remarks:

Cognitive testing of an end-of-life care and medical end-of-life decision-making questionnaire in a Trinidad and Tobago context

INTERVIEW GUIDE

(Opening Script)

You may recall from the Participant Information sheet we sent to you that I would like to ask you to fill out a questionnaire about end-of-life care and medical end of life decision-making in Trinidad and Tobago. The questionnaire is based on a review of existing instruments but has not been validated in the context of Trinidad and Tobago, and we are aiming to do so in this project. We plan on conducting a survey once all the questions are validated. For this project, we are keen to find out how you, as a physician in Trinidad and Tobago, understand and perceive the questions.
There are two steps to this process:

- First, I will like you to complete this questionnaire based on a typical end of life scenario that you might come across in your work (for example, you can think of a specific case you had).
- Second, after you have completed the questionnaire, I will like to ask you about your perceptions of the different questions.

The questions are not designed to elicit personal information about you or circumstances surrounding actual cases you are or have been involved with. Nonetheless, we will treat your responses as confidential. You will be assigned a unique code. Only the research group will have access to your answers, in a way that does not tie your answers back to you, personally, as a respondent. We plan to publish our findings in a peer-reviewed scientific article, but publication of the results will be presented in a way that does not identify any respondent.

If you agree to participate in this interview, and I ask a question that, for whatever reason, you would rather not answer, just say so and we can skip ahead to the next one. Also, if you will like to stop altogether at any point, just say you would like to stop and we can end the interview. If you withdraw partway through, you may ask that your responses be withdrawn from the study.

Is there any other information you would like to have about this study?
No.
Yes: What further information would you like? Answer queries. If you cannot answer queries inform participant you will need to get back to them with the answers. Request time and appropriate phone number to do so.

Are you willing to participate in this interview now?
Yes: OBTAIN SIGNED CONSENT FORM AND PROCEED.
No: DO NOT PROCEED. Thank participant for considering request for interview. Ask if they would be willing to state why they do not wish to participate. Record response. Thank participant for their time and end the interview.

STEP1:
Provide questionnaire to participant

- Remind them to think about the latest death they attended, (if they are hesitant, ask them to think about an actual case), and to not provide any identifies such as places, or individual or facility names.
- Provide participant with highlighter pen. State: Here is a highlighter pen to assist you to insert a place marker on the questionnaire to remind you about any issues you would like to raise with me after you complete the questionnaire, for example, if you think a question is unclear or does not make sense in a Trinidad and Tobago context.
- Request to record time taken to complete the questionnaire and begin timing.
- Address and record issues if they are raised.

STEP 2:
Conduct post-questionnaire Interview
I will now like to discuss your perceptions of the questionnaire. The purpose of the questions I am going to ask you is to make sure the survey is capturing the information we want to capture and to get feedback on your experience in completing the questionnaire. I have a list of questions I will like to work though. Some are about the questionnaire in general and some relate to specific questions. Shall I begin asking the questions?

YES: Proceed
NO: Address any issues they raise. Record issues and your responses. If they do not wish to proceed thank participant for considering request for interview. Thank participant for their time and end the interview.

PART I – General Questions

I would like to ask you some general questions that are not part of the questionnaire questions.

1. What do you think of when I say palliative care?

2. What type of care do you consider as palliative care?

3. Is there anything in the questionnaire that does not reflect the clinical realties in a Trinidad and Tobago context?

4. Should any questions be deleted? If so which ones and why?

5. Are any important questions missing? If so, what are they?

6. Are the questions presented in a logical sequence? If not, how could it be improved?

7. Does the questionnaire take too long to complete?

☐ Yes

☐ No

8. Are the routing directions (for example, go to question x) clear enough?

9. Is the layout and organisation confusing? If so, how can it be improved?

PART II – Specific Interview Questions

We are interested in your thoughts about the questions posed to you in the questionnaire and will like to spend a little more time on them.

No.	**Evaluation**	**Comments** (Own comments in brackets)
1	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
2	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
3	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
4	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
5	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
6	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
7	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
8	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	

9	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
10	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
11	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
12	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
13	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
14	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
15	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
16	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
17	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	

18	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
19	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
20	☐ Clear ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
21	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
22	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
23	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
24	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
25	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	
26	☐ Clear ☐ Confusing / unclear ☐ Difficult to answer ☐ Unimportant ☐ Confronting ☐ Important answer options missing	

Supplemental 2. General Questions: Numbers 1 and 2

END-OF-LIFE CARE RESEARCH GROUP

Trinidad & Tobago Medical Association

St. George's University
THINK BEYOND
Grenada, West Indies

Question 1: What do you think of when I say palliative care?	Question 2: What type of care do you consider as palliative care?
"Care when cure is no longer possible."	"Everything from social, spiritual, financial, emotional, physical, family support . . ."
" . . . providing care to patients with serious illness . . . at any point of the disease . . . to relieve symptoms . . . the patient may not have long to live."	"All the care provided to relieve symptoms . . . including physical and mental stress, for the patient and family."
"Care of patients with advanced and incurable illnesses . . . any disease that can shorten a patient's life . . . "	"Both comfort and supportive care."
"End-of-life care . . . doesn't necessarily mean withholding treatment . . . but looking at a terminal disease and symptom management related to advanced disease."	" . . . could be at different levels . . . for example at a hospice, it could be managed by a palliative care physician . . . it could also be care that is managed by a family physician, or oncologist . . . involves managing symptoms related to disease."
"Preparing for death and to meet your maker. . . there is no cure . . . comfort, pain relief, support, dealing with the personal issues in terms of death and dying."	Caring for persons with "any terminal illness like AIDS, diabetes, autoimmune diseases."
"The preparation of human mind and body as it comes towards the end of life. . . palliative care starts differently for different patients. . . sometimes while someone is undergoing. . . active management they may need psychological palliative care support prior to switching over from active management into palliative management medically. . . other patients may need active and palliative management at the same time".	". . . If we are not actively treating a patient to remission and or cure, then the rest is termed palliation . . . if we are not seeking a cure we have to psychologically prepare a patient for the possibility of end of life. . . certainly symptom control and the medical management surrounding that".
"End-of-life care . . . to alleviate suffering and pain, symptomatic relief more that curative".	"To provide the basic humanitarian aid like analgesia, food and hydration".
"Palliative care is doing whatever is necessary to improve the quality of life in patients with a terminal illness where cure is not a viable option".	"Looking at patients with terminal illness, like patients with cancer and non-cancer conditions that medical therapy has little role for in terms of prolonging life (patients with heart failure, renal impairment, muscular paralysis".

The patient is in the best comfort at the end stage of life when we cannot treat the underlying cause of their illness. Focus on supportive care and comfort.	Care when the underlying pathology is untreatable.
“Working with patients who are terminally ill, and trying to get people to accept that this is something we cannot cure . . . I use the phrase, landing the plane as gently as possible. By people I mean patients and their relatives, patients take a while to imagine that the horizon is a lot closer than they imagine”.	“I define it by aim of treatment not by interventions. . . for example, chemotherapy in stage 4 cancer is effectively a palliative exercise. . . some people associate palliative care only with the use of opioids but I don’t. I think opioids can be used anytime through the spectrum of illness, similarly, chemotherapy has its place but not right at the end”.
“Comfort care and quality of life”.	“Holistic care, not only for the patient’s physical symptoms but also their emotional and psychological symptoms as well and also care for the family”.
“Care of anybody with a condition that can’t be cured . . . I’m concerned with people’s quality of life and happiness . . . not focusing only on the death and dying aspect . . . the goal is to help people die well, a good death”.	“Palliative care should start as you get a bad diagnosis from your GP or a specialist physician for a life limiting condition . . . people think it’s really medical but it involves discussions like telling people what to expect for the future, that the disease course is uncertain especially with the none cancer diseases to really mentally prepare people . . . yes there is symptom control but the real hard stuff is the discussions from the time somebody has a bad diagnosis.
“Care for the dying. By definition is supportive care, non-curable . . . what we refer to in general practice as trying to avoid suffering, to minimise pain and suffering while the condition or disease process takes its natural course for patients who are beyond any cure or treatment”.	“Pain relief, adequate nutrition, psychological support, management of antecedent things like the chronic complications of bedrest, for example, bedsores”.
“A clinical framework which attempts to discern the end of life preferences of the client, in terms of identifying a policy or a living will as to how they will like to prepare for the terminal phase for a chronic disease, and not necessarily confined to cancer. Especially in the knowledge that at some point of a chronic disease, as clinicians, we do not necessarily improve the outcome but we prolong the life, we prolong the life without improving health, with the knowledge that there is a certain timespan to the terminal phase of any disease process and since we can reasonably determine when the terminal phase will be, it’s in my opinion seems reasonable to plan with the patient on how to prepare for the terminal phase ”.	“Palliative care attends to the physical needs, the psychological needs, it also focuses on the caregiver and support of the caregiver, as what I refer to the spiritual or existential need of the patient. It’s trying to balance all these things for good quality of life or reasonable quality of life at the end. Of course, it requires a lot of things, an assessment of the patient, it requires communication, it requires an advanced plan, a management plan of how you are going to do it, which should be dynamic because things may change, the expectations of the client and family may change, there is also the issue of active verses passive actions, doing active things to change an outcome such as instituting care at the end and knowing what the patient wants, e.g.; to be intubated, to receive chest compressions, to receive medications and their effects. Also, who has the last say, your proxy, a living will or both”.
“The patient is at end stage disease which will contribute to the patient’s death in a relatively short space of time”.	“Speaking from the medical and psychological point of view, palliative care includes pain control, hydration, looking after the organs in the best way possible, trying to control the blood pressure (comorbidities e.g.; diabetes),

	maintaining a quality of life for the patient until death. Also, to ensure psychologically the patient, family and caregivers to go through the process of accepting death”.
“Support, people dying with dignity, care for terminal patients at the end of life, inclusive of caregivers (family, formal and informal), bereavement and financial planning”.	“Care at the end of life, palliative, hospice, supportive care for any kind of illness that is incurable, e.g.; in oncology, symptom management like nausea and vomiting, making referrals and appointments, helping patient cope”.
“Keeping the patient comfortable in the later stages of life usually when there is no curative mechanism available for her condition”.	“Includes an entire spectrum including social, emotional, psychological, spiritual, pain relief, everything we can do to make them comfortable. Curative care is outside the palliative care spectrum”.
“Making life as comfortable for someone who has an illness that will limit his/her own life. Comfort care when cure is not possible. Holistic care that involves families as well as patients”.	The participant thought that this question was a repeat of the pervious one and may not yield any additional information.

Supplemental 3: Cognitive interviews. Participant perception of questions, their suggestions or comments, and changes made to the questionnaire.

Section	Question #	Draft questions	Issue/participant suggestion or comment	Change or justification for no change
General	1	Was this death sudden and totally unexpected?	• Confusing question because the patient is terminal and receiving palliative care, and asking if the death was sudden and unexpected is contradictory, consider keeping 'sudden' only. • Consider reversing the order of questions 1 and 2. • The question is confusing, consider replacing it with 'Were you the attending physician prior to the death of this individual'.	• No change. Question intended to identify persons dying suddenly and less likely to have received end-of-life care. • No change – filter question from patient to physician. • Issue was addressed by including in the cover page instructions stating that the questionnaire is intended for the 'attending physician'.
	2	When was your first contact with the patient?	• Answer option is asking two responses 'before or at the time of death'. • Include space for physicians to write the time they had known the patient.	• Changed response option to 'at the time of or after death'. • Change made.
Care and Treatment concerning this patient prior to his/her death	3	Of the following, which treatment goal was given priority in the last 7 days of life? *(Choose only one answer, i.e. the main treatment goal)*	• Participants thought it difficult to select only one answer option to this question. • Consider including an answer option for the promotion of relative/s of caregiver wellbeing.	• No change made. Our aim was to get the primary treatment goal for the patient and having multiple answer options would have defeated this purpose.
	4	Which of the following treatment(s) were given in the last 30 days of life? (*multiple answers possible*)	• Answer options are standards of care in an ICU setting. Add analgesics to the answer options as the previous question mentioned maximization of comfort as an answer option.	• Included analgesics as the first main answer option.
	5	In which of the following places did the patient receive care in the last 30 days of life? (*multiple answers possible*)	• Consider adding an answer option 'I don't know'.	• No change made. An I don't know option was deferred to avoid this being a default option.
	6	Which of the following caregivers, besides yourself, were actively involved in the care for the patient in the last 30 days of life? (*multiple answers possible*)	• Remove answer option 'volunteer' since there are not many volunteers. Social worker is more applicable to the hospital setting.	• No change made. Answer options can be used in future national surveys and comparisons can be made cross nationally.
	7	Who, to your knowledge, was present when the patient died? (*multiple answers possible*)	• Older persons requiring palliative care are often in geriatric homes, consider adding a response option to include 'geriatric home staff'. • Consider adding a space for who the family member is/was in the answer options.	• Added answer option 'geriatric home staff'. • No change made. Answer option 'other' can serve this purpose.
	8	What was the patient's preferred place of death?	• Reposition this question as it flows better from question #7.	• Change made.

	9	Did this patient receive any <u>*palliative care*</u> (at home, in a hospital or elsewhere)? (*multiple answers possible*)	- Include a definition of palliative care in the questionnaire. - A participant found it odd to see a footnote (the definition of palliative care) in a questionnaire and did not read it.	- *Added a definition of palliative care (questions 9 through 11 specifically mention palliative care). - The definition's font colour was made different from the rest of the text.
	10	When did the patient first receive palliative care before his/her death?	- No issues with this question	- No change required.
	11	For which reason(s) was <u>*palliative care*</u> not initiated? (multiple answers possible)	- Answer option 'palliative care was not or insufficiently meaningful' is confusing, consider removing and replacing it with 'unaware palliative care services exist' or 'unaware how to access palliative care services in my region'. - Consider adding 'Financial constraints' to answer options. - Answer option 'palliative care was not or insufficiently meaningful' was unclear. Consider including directions at the beginning of the questionnaire to remind physicians that responses are from their experience and knowledge of what occurred.	- Changed response option to 'unaware how to access palliative care services in my region'. - 'Financial constraints' added to answer options. - This answer option was removed from the questionnaire. Text was added at the beginning of the questionnaire to address this concern: 'What is asked of you? – Please try to recall as carefully as possible this death, where you were the ATTENDING PHYSICIAN (if necessary, using the patient's file or medical records) and complete this questionnaire as accurately as possible. Please read the accompanying letter to this questionnaire prior to completing the questionnaire'.
Medical Practice	12	Please indicate whether you prescribed or administered any of the following drugs to treat or alleviate symptoms this patient had in the last 7 days of life? (multiple answers possible)	- Consider adding drug options such as; laxatives, antiemetic and removing Propofol and lidocaine; include answer option for a drug category for dementia or restless patients e.g.; chlorpromazine; include an answer option for Diazepam. - Leave more space for writing 'other' drugs used.	- These changes were made to the questionnaire. - Additional space added.
	13	In your opinion, could the administration of these drugs have influenced the timing of death?	- The word "expedited" is confronting and is understood as hastening death, rephrase to 'transitioning the death'.	- Recurring issue, the word was changed from 'expedited' to 'influenced'.
	14	Why were no drugs used to alleviate symptoms? (multiple answers possible)	- Consider adding 'Financial constraints' to answer options.	- 'Financial constraints' added to answer options.
	15	Did you withhold and/or withdraw any of the following potentially life-prolonging treatment(s)?	- None of the response choices apply to home care. - Consider including a timeframe for this question	- No changes made. Suggestions are beyond the scope of this study.

		(multiple answers possible)	e.g., 14 days. • There should be a follow up question to #15 to ask why did the physician withhold treatment, with answer options 1) No benefit to the patient 2) Financial constraints of the patient or family 3) To save the patient discomfort from invasive treatment.	• No changes made. Suggestions are beyond the scope of this study.
	16	In your opinion, could the withholding and/or withdrawing of treatments have influenced the timing of death?	• The use of ‘expedited’ in the question is a word not often used in the local context, consider changing. • Response option “yes, certainly expedited the timing of death” likely not to be selected by physicians.	• Changed the word ‘expedited’ to ‘influenced’. • The word ‘expedited’ was removed from answer options and replaced with ‘brought forward’.
Decision-Making	17	Did you discuss with the patient the various options related to end-of-life treatments? (multiple answers possible)	• A follow-up question to #17 as to why there was no discussion with the patient is missing.	• Question 18 was added.
	18	Why was there no discussion with the patient about the various options related to end-of-life treatments? (multiple answers possible)	• Consider adding an answer option, ‘relatives did not want the physician to discuss with the patient’. • Include more space to write for answer option ‘other’.	• No change made as there is an answer option for ‘other’. • Additional space included for ‘other’.
	19	With whom, of the following, did you discuss the end-of-life treatment options for this patient? (multiple answers possible)	• In the answer options, consider splitting “The patient’s partner or relatives” into two separate options.	• No change made. Answer option ‘other’ can serve this purpose.
	20	As far as you know, did the patient ever express a wish for the end of life to be hastened?	• No issues with this question.	• No change required.
Information regarding yourself as a physician	21	What is your gender?	• No issues with this question.	• No change required.
	22	How long have you practiced as a physician?	• The question ‘how long have you practiced as a specialist in patient care’ is confusing, consider changing to specialist in your field for both hospital physicians and general practitioners.	• The question was rephrased to ‘how long have you practiced as a physician’.
	23	Have you ever had any formal training in palliative care? (multiple answers possible)	• Consider removing ‘palliative care for physicians’ from 3rd answer option. • Consider asking physicians whether they want training in palliative care.	• Change made. • No change. Beyond the scope of this study. • Researchers added the option for multiple answers to the question.
	24	Do you consider you have enough expertise to communicate adequately with patients at the	• Answer option ‘no’ is confronting.	• No change to answer options made but changed the ordering of responses by moving ‘no’ from last to first

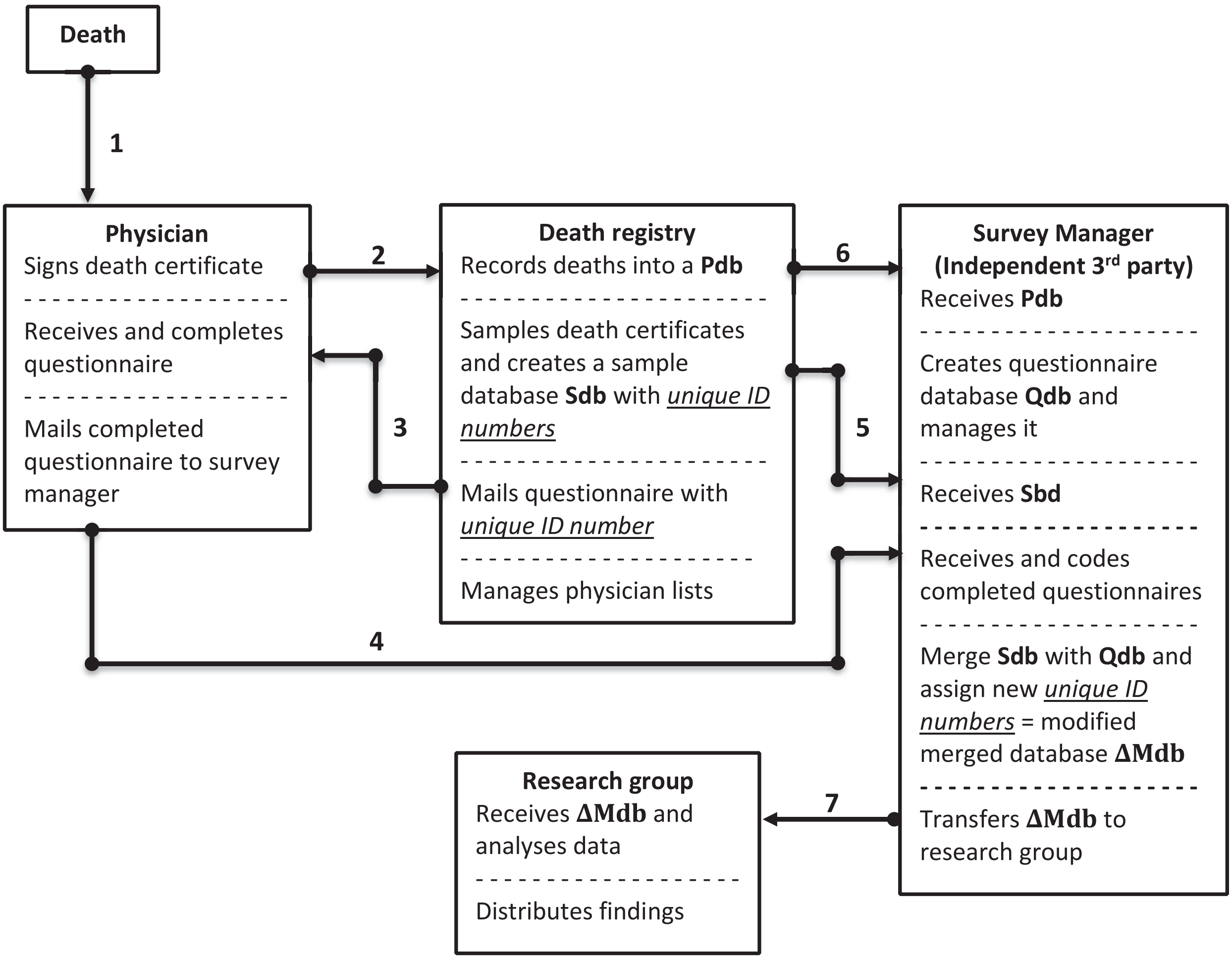
		end of life? (multiple answers possible)	• Include a response to indicate having 'some experience' or 'some training'.	option: ○ No ○ Yes, through experience/informal training ○ Yes, through formal training • Question was rephrased from '*Do you consider you have enough expertise to deal with patients at the end of life*'. • Researchers added the option for multiple answers to the question.
	25	Do you consider you have enough expertise to communicate adequately with family of patients at the end of life? (multiple answers possible)		• Question added – researchers added a follow-up question to #24.
	26	Do you feel sufficiently supported, by the current protocols of care in Trinidad and Tobago, with your preferred management and decision-making at the end of life for your patient?	• This question isn't applicable as there are no laws regarding end-of-life decision making in Trinidad and Tobago. • In the question, consider changing 'healthcare regulations' to 'protocols of care'	• Question was rephrased from *'Did your perception of the law, as it applies in Trinidad and Tobago, inhabit or interfere with your preferred management and decision-making at the end of life for your patient*'. • Change made to question.

Abbreviations: ICU – Intensive Care Unit;

***By Palliative Care we mean "Care that helps people live their life as fully and as comfortably as possible when living with a terminal illness. It identifies and treats symptoms which may be physical, emotional, spiritual or social."[28]**

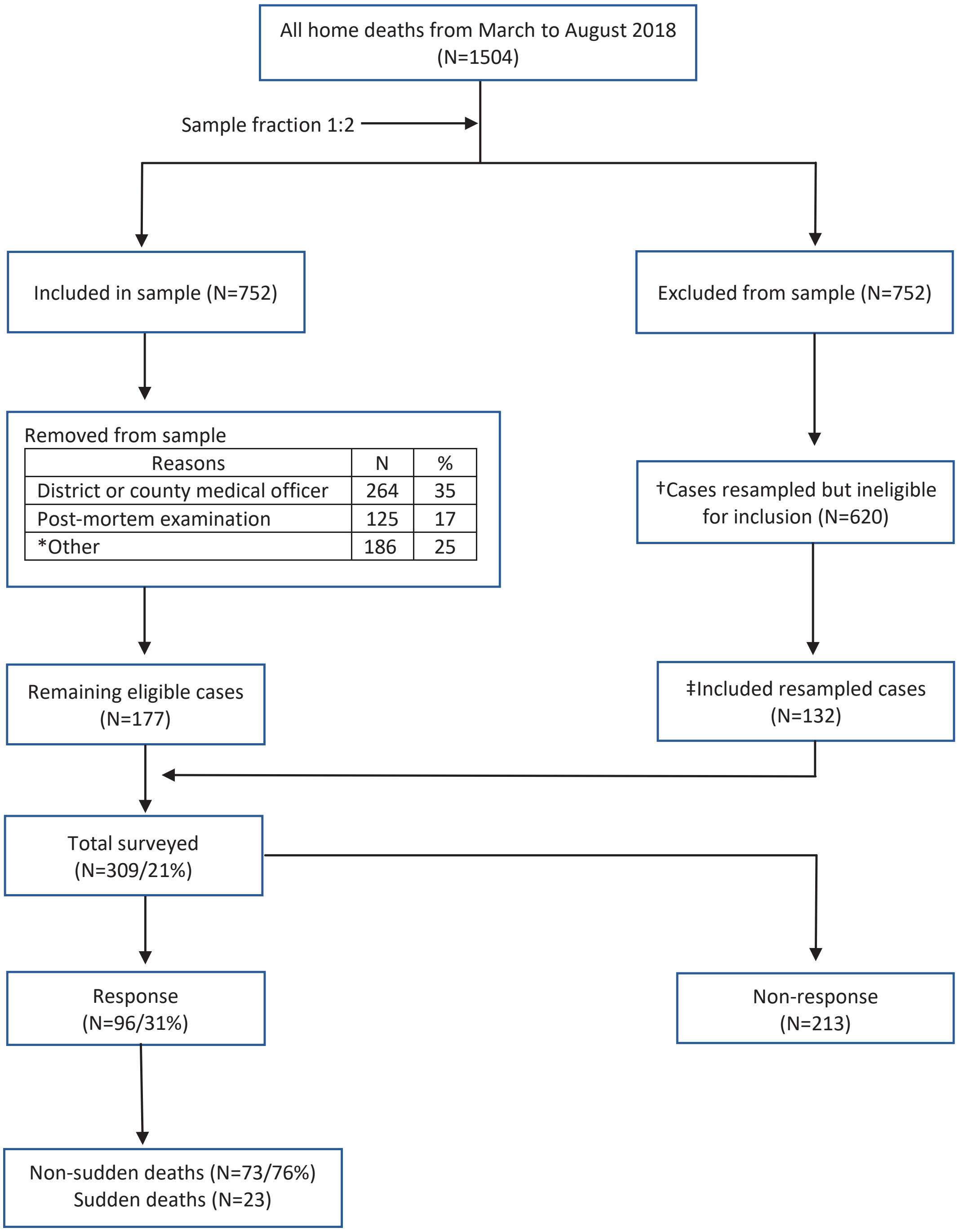
CHAPTER 7

Appendix 1. Schematic of mailing procedure



Abbreviations: Pbd – population database, Sdb – survey database, ID – identification, Qdb – questionnaire database, **Δ**Mdb – merged database.

Appendix 2. Flowchart of sampled death certificates



Removed from sample

Reasons	N	%
District or county medical officer	264	35
Post-mortem examination	125	17
*Other	186	25

*Other includes: physician certifying the death case had indicated to not want to participate, physician could not be located, illegible writing on death certificate, and saturation of questionnaires per physician.

†Cases ineligible for resampling because: death certificates certified by a district or county medical officer, cases transferred for post-mortem examination, cases were past the three-month cut-off time, and reasons listed as ‘Other’ above (physician did not want to participate, physician could not be located, illegible writing on death certificate, and saturation of questionnaires per physician).

‡Resampled cases were sequentially selected within the same month of the case that a sample was removed.

Appendix 3. Sociodemographic distribution of characteristics of all home deaths surveyed and for all cases that a response was received

	Cases surveyed		Cases with response		
	*N	%	†N	%	P-value
All deaths	309	100	96	100	
Sex					0.12
Male	142	46.3	52	55.3	
Female	165	53.3	42	44.7	
Age					0.62
18 thru 49	10	3.3	5	5.3	
50 thru 59	20	6.5	6	6.4	
60 thru 69	49	16.0	9	9.6	
70 thru 79	74	24.2	22	23.4	
80 thru 89	95	31.0	34	36.2	
90 thru highest	58	19.0	18	19.1	
Cause of death					0.85
Cardiovascular diseases	84	27.4	30	31.9	
Malignancies	69	22.5	17	18.1	
Diabetes mellitus	67	21.8	21	22.3	
Cerebrovascular diseases	27	8.8	6	6.4	
Liver and kidney diseases	21	6.8	9	9.6	
Nervous system diseases	18	5.9	6	6.4	
Other causes of death	21	6.8	5	5.3	
Sudden					‡
Yes	NK	NK	23	24	
No	NK	NK	73	76	

*2 missing cases for sex and cause of death, 3 missing cases for age
†2 missing cases for sex, age and cause of death
% are valid percentages
P-values <0.05 were considered significant
‡P-values could not be calculated due to empty cells
Abbreviations: NK – Not known