
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.\(^2\) 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.\(^7\) 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.\textsuperscript{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,\textsuperscript{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.

\textbf{METHODS}

\textbf{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.\textsuperscript{19}

\textbf{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

<table>
<thead>
<tr>
<th>Years</th>
<th>1999</th>
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<tr>
<td>All deaths (N)</td>
<td>10014</td>
<td>9479</td>
<td>9753</td>
<td>9797</td>
<td>10206</td>
<td>9872</td>
<td>9885</td>
<td>9668</td>
<td>9654</td>
<td>10463</td>
<td>9693</td>
<td>10219</td>
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<td>Sex</td>
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<tr>
<td>Male</td>
<td>55.2%</td>
<td>55.6%</td>
<td>56.2%</td>
<td>56.8%</td>
<td>56.9%</td>
<td>56.8%</td>
<td>57.7%</td>
<td>56.5%</td>
<td>56.7%</td>
<td>57.4%</td>
<td>57.2%</td>
<td>57.0%</td>
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<tr>
<td>Female</td>
<td>44.8%</td>
<td>44.4%</td>
<td>43.8%</td>
<td>43.2%</td>
<td>43.1%</td>
<td>43.2%</td>
<td>42.3%</td>
<td>43.5%</td>
<td>43.3%</td>
<td>42.6%</td>
<td>42.8%</td>
<td>43.0%</td>
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<td>Age</td>
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<tr>
<td>0 thru 59</td>
<td>36.3%</td>
<td>38.8%</td>
<td>38.1%</td>
<td>37.7%</td>
<td>37.4%</td>
<td>36.5%</td>
<td>36.9%</td>
<td>36.5%</td>
<td>36.9%</td>
<td>36.7%</td>
<td>37.8%</td>
<td>34.6%</td>
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<td>60 thru 69</td>
<td>17.6%</td>
<td>17.3%</td>
<td>16.9%</td>
<td>16.9%</td>
<td>16.5%</td>
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<td>17.8%</td>
<td>17.4%</td>
<td>17.3%</td>
<td>17.5%</td>
<td>17.7%</td>
<td>18.2%</td>
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<td>70 thru 79</td>
<td>22.1%</td>
<td>21.5%</td>
<td>21.1%</td>
<td>21.1%</td>
<td>21.2%</td>
<td>20.3%</td>
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<td>20.4%</td>
<td>20.7%</td>
<td>20.2%</td>
<td>19.7%</td>
<td>20.4%</td>
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<tr>
<td>80 thru 89</td>
<td>18.2%</td>
<td>16.8%</td>
<td>17.5%</td>
<td>17.6%</td>
<td>18.5%</td>
<td>18.8%</td>
<td>18.2%</td>
<td>18.7%</td>
<td>18.0%</td>
<td>18.1%</td>
<td>17.4%</td>
<td>19.2%</td>
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<tr>
<td>90 thru highest</td>
<td>5.8%</td>
<td>5.6%</td>
<td>6.3%</td>
<td>6.7%</td>
<td>6.4%</td>
<td>6.5%</td>
<td>7.0%</td>
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<td>7.0%</td>
<td>7.5%</td>
<td>7.4%</td>
<td>7.6%</td>
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| 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% | 14.7% | 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
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, 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 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.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. 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. 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 can further impede provision of home care. In the absence of policy like, a do-not-hospitalize option that exists in other countries, or supportive environments that attempts to optimise home deaths 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.

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. 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, 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, 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. A trend usually linked to national, or at least large-scale EOLC programmes or strategies, e.g., involvement of palliative care services, the UK hospice system or the introduction of the hospice benefit scheme in the USA. 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.\textsuperscript{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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archived de-identified datasets. The data of this study are with the first author and are available upon request.

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REFERENCES


