ORIGINAL ARTICLE

A review of the trends in the first six years of a palliative care unit in Trinidad and Tobago

Karen Cox[1], Stacey Chamely[1], Astra Chang[1], Sandhya Maharaj[2], Isioma Isitor[1], Raisa Abdullah[1]

[1] Palliative Care Unit, Caura Hospital, North Central Regional Health Authority, Trinidad and Tobago
[2] Department of Public Health and Primary Care, Eastern Regional Health Authority, Trinidad and Tobago

Corresponding author:
Email kcoxseig@gmail.com

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Abstract

Objectives:

To present key data accumulated from the first six years of a publicly funded Palliative Care Unit (PCU) in Trinidad and Tobago.

Methods:

This was an observational, descriptive, retrospective study. Data was sampled from five (5) service areas: admissions to the PCU, out-patient clinic, hospital consultations, family meetings and telephone calls. Demographic data, reason for referral, diagnosis, time to consultation and outcome data were collected.

Results:

The Palliative Care Unit was accessed by 2579 patients between 2014 - 2020. Ages ranged from 3-103 years. There were 1004 unique in-patient admissions, most of whom fell in the age range 62-82 years. 83% had a documented cancer diagnosis. 90% of patients spent less than 30 days at the PCU. Discharge rate was 25%. Most out-patient clinic referrals were for symptom management - 90.8% of these had cancer. Median time from palliative care review at out-patient clinic to death was 34 days (Interquartile range (IQR) 12-107 days). For the hospital consultation service, 82.8% had a cancer diagnosis. Median time from palliative care review to death was 11 days, Interquartile range (IQR) 4-39 days.

Conclusion:

The Caura PCU meets the needs of a small proportion of palliative patients in Trinidad and Tobago. The service is accessed mostly by patients with cancer, and referrals are frequently made late in the disease trajectory. This service needs to be expanded to include a community/ home-based service and a paediatric service. Palliative care needs to become integrated throughout the health service in Trinidad and Tobago.

Introduction

Palliative care is an approach that aims to improve the quality of life of patients and families who are facing life-limiting illnesses.[1] It is holistic care that addresses psychological, spiritual and physical domains. The provision of palliative care is the ethical duty of health systems.[2] Equitable access to palliative care requires the integration of palliative care at all levels of the health system, from community-based care to tertiary care.[2]

Palliative care is indicated for the relief of serious health-related suffering, whatever its underlying cause[3] and for persons of all ages.[3] It encompasses the care of persons with cancer as well as other non-communicable diseases (NCD's) such as cardiovascular diseases, chronic respiratory diseases, diabetes, renal failure, chronic liver disease, multiple sclerosis, Parkinson's disease and dementia.[2] It includes diseases with infectious aetiologies such as Human Immunodeficiency Virus (HIV) and drug-resistant tuberculosis.[2]

The World Health Authority (WHO) estimates that 40 million people need palliative care worldwide. It is projected that by 2060 there will be an 87% increase in the palliative care need, with the highest proportionate increase in low-income countries.[4] The rising burdens of cancer and other NCD's, and the growing elderly population are expected to contribute heavily to the future palliative care need.[4]

Research mapping global palliative care services shows that at best, isolated services exist in some Caribbean territories, with others having no known activity.[5] Trinidad and Tobago's level of palliative care development is categorized as isolated palliative care provision,[5] indicative of patchy palliative care services, few in number relative to population size.

Currently in Trinidad and Tobago, there are six palliative care services. Of these, three Non-Governmental Organizations (NGOs) provide hospice care for patients with either cancer, acquired immunodeficiency syndrome (AIDS) or any life limiting illness and three of the five regional health authorities provide palliative care services. Two Regional Health Authorities (RHAs) provide community outreach services to patients within each respective region and one has an established palliative care unit, inclusive of inpatient and outpatient care. As a result of the distribution of these services, there are significant disparities in access to palliative care across the country.

This study focuses on the established palliative care unit in one of the RHAs, the Caura Palliative Care Unit (PCU). Key data and trends over the first six (6) years of this Palliative Care Unit in Trinidad and Tobago will be presented. This study aims to inform practice locally and regionally for sustainable Palliative Care services in other resource-constrained settings.

Methods

Study setting

The PCU is unique in being an NGO/RHA partnership, one between the Palliative Care Society of Trinidad and Tobago (PCSTT) and the North Central Regional Health Authority (NCRHA). It was opened in August 2014 and meets national need, accepting referrals from all RHA's, and from both private and public health sectors. It offers an inpatient service, a hospital-based consulting service (primarily at the nearby Eric Williams Medical Sciences Complex, EWMSC, but also at Mt. Hope Women's Hospital), an out-patient clinic and a telehealth service. The Unit is staffed by nurses and physicians, with access to a team of medical social workers, psychologists and volunteer chaplains. This core team delivers care to all four service areas.

Study Design

Ethics approval to conduct the study was obtained from the Ethics Committee of the North Central Regional Health Authority. This was a retrospective study of patients which utilised all the PCU's services for a period from August 2014 to December 31st 2020. During 2014, only five months of data were recorded, while for all subsequent years, a full twelve months of data were recorded.

Data Collection

The dataset was obtained by systematic sampling from two sources: the PCU's admission ledger and the PCU's electronic database. Data on the inpatient service was drawn from the hand-written admissions ledgers. For the other four service areas (out-patient clinic OPC, family meetings, telephone calls and hospital consultations), data was extracted from the computerized database. All available records for the study period were included. Data on family meetings was complete only from 2016 onwards, when recording of these as separate clinical encounters began. Data on hospital consultations represented in-patient consultations done at EWMSC and Mt. Hope Women's Hospital only. For all patients, demographic data and reason for referral were collected. For patients admitted to the PCU, data on diagnosis, length of PCU stay, outcome of admission, time from admission to death and place of death were collected. For clinical encounters at the outpatient clinic and for hospital consultations, data collected was diagnosis of cancer or non-cancer, the interval between referral and palliative care consultation and the interval between palliative care consultation and death. Specific cancer or non-cancer diagnoses were not available for these encounters. The numbers of telephone consultations and family meetings done per year were collected.

Data Analysis

The data set was dumped from Microsoft Access to the spreadsheet programme Excel and cleaned manually in Excel. The Excel file was read using Python and the Pandas library. All statistical analyses were done using the built in Pandas function.

Results

Between 2014 and 2020, the service was accessed by two thousand five hundred and seventy-nine (2579) unique patients. Females (56.5%, n=567) accessed the unit more frequently than males (43.5%, n=437). There were one thousand and four (1004) unique admissions i.e., individual patients, admitted to the PCU, with 11%, n=130, more females than males. Patient demographic data, the duration of stay at PCU and the outcome of stay are displayed in Table 1.

Table 1. Demographic and Outcome Data for PCU Admissions

		No. of Patients (%)
Total		1004
Male		437 (43.5)
Female		567 (56.5)
Age Ranges in years	16 - 19	5 (0.49)
	20 - 40	42 (4.1)
	41 - 61	328 (32.6)
	62-82	509 (50.7)
	> 83	120 (11.9)
Duration of Stay	<24 hours	80 (8)
	1-7 days	402 (40)
	8-30 days	422 (42)
	31-90 days	91 (9)
	>90 days	9 (0.9)
Outcomes	Discharged	248 (25%)
	Transferred	24 (2%)
	Died	732 (73%)
	Re-admitted	42 (4%)

Of the 1004 patients admitted over the study period, approximately 73%, n=732, died at the PCU and 25%, n=248, were discharged. Only 2%, n=24, were transferred to other institutions. Of those transferred, 41%, n=10, went to an acute hospital, 41%, n=10, to an elderly care home, 8%, n =2, discharged against medical advice, 4%, n=1, moved to another hospice, and 4%, n=1, was transferred to a cancer centre for chemotherapy. There was a 4%, n=42, readmission rate, with a readmission being defined as an admission to the PCU within one month of discharge. Patients readmitted after longer intervals were not captured.

Admission data for PCU

Most patients admitted had a diagnosis of cancer (Table 2). (83%, n=830) - lung (19.9%, n=165) and breast cancer (19.4%, n=161) were the most common, followed by colon (10.2%, n=85), prostate (9.3%, n=77), pancreatic (6.6%, n=55) and endometrial (4.5%, n=37). (Table 2) Among the non-cancer admissions, cerebrovascular accident (29.2%, n=33) was the commonest diagnosis. Dementia (16.8%, n=19), end stage renal disease (13.3%, n=15) and chronic heart failure (10.6%, n=12) followed. For 6%, n=61 of those admitted, data on specific diagnosis was missing.

Table 2. Top Cancer and Non-Cancer Diagnoses for PCU Admissions

Diagnosis Cancer, no. (%)	Lung	165 (19.9)
	Breast	161 (19.4)
	Colon	85 (10.2)
	Prostate	77 (9.3)
	Pancreatic	55 (6.6)
	Endometrial	37 (4.5)
	Rectal	33 (4.0)
	Cervical	28 (3.4)
	Ovarian	27 (3.2)
	Unknown Primary	21 (2.5)
	Other Cancer diagnoses	141(17)
	Total	**n= 830**
Diagnosis Non-Cancer, no. (%)	Cerebrovascular Accident	33 (29.2)
	Dementia	19 (16.8)
	End Stage Renal Disease	15 (13.3)
	Chronic Heart Failure	12 (10.6)
	Gangrene	7 (6.2)
	Aspiration Pneumonia	7 (6.2)
	End Stage Liver Disease	4 (3.5)
	AIDS	3 (2.7)
	GI Bleeding	2 (1.8)
	Hypoxic Brain Injury	1 (0.9)
	Other Non-Cancer diagnoses	10 (8.8)
	Total	**n= 113**
Undocumented diagnoses. no. (%)		**61 (6%)**

Table 3. Reason for Referral by Service

	Hospital consultations	OPC	Inpatient Service
Symptom Control, no. (%)	576 (36.1)	1601 (60.1)	54 (5.3)
Psychosocial Support, no. (%)	614 (38.5)	921 (34.6)	-
End of Life Care, no. (%)	404 (25.3)	142 (5.3)	514 (50.6)
Respite (%)	-	-	83 (8.2)
Not documented (%)	-	-	365 (35.9)
Total Number of Encounters (n)	1594	2664	1016

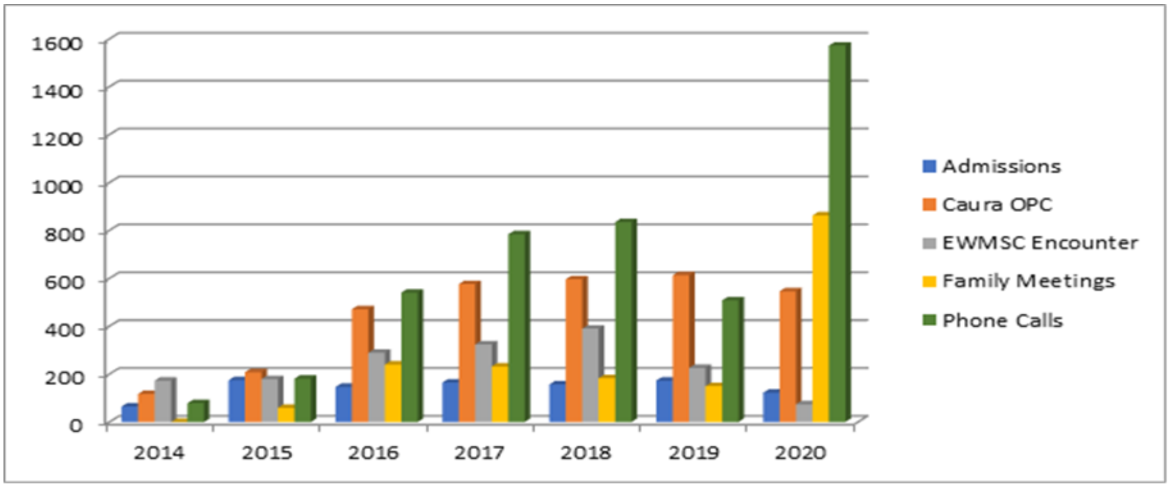
OPC = Out-patient Clinic

Table 4. Diagnosis, Service Responsiveness and Outcomes

	Outpatient Clinic	Hospital Consultations
Cancer, no. (%)	713 (90.8%)	819 (82.8%)
Non-Cancer, no. (%)	72 (9%)	170 (17.1%)
Median time from referral to PC review, days (IQR)	7 (2-15)	1 (0-3)
Median time from PC review to death, days (IQR)	34 (12-107)	11 (4-39)

IQR, interquartile range

Figure 1: Number of encounters by service area



Abbreviations: PC, palliative care; IQR, interquartile range

Reason for Referral

The reasons for referral to the different divisions of the service are displayed in Table 3.

Approximately half of all admissions 50.6%, n=514, were referred for end-of-life care, with smaller numbers being referred for respite and symptom control. There was no documentation in the admission ledger of reason for referral in approximately 35.9%, n=365, of cases.

Referrals for in-patient hospital consultations were for psychosocial support and symptom control in similar proportions (38.5%, n=614 and 36.1%, n=576 respectively), with smaller numbers (25.3%, n=404) referred for end of life care. The outpatient clinic was most frequently accessed for symptom control (60.1%, n=1601).

Hospital consultation and OPC Services

Table 4 outlines details of the OPC and hospital consultation services.
Of those patients referred to OPC, 90.8%, n=713 had a cancer diagnosis. Among hospital consultations, 82.8%, n=819 had cancer diagnoses. The median time from referral to OPC consultation was seven days. For hospital consultations, the median referral to consultation time was one day. Median time to death from PC review was thirty-four days for patients seen at OPC and eleven days for those seen as hospital consults. For the entire study period, referral to consultation time for hospital consultations remained at a median interval of 1-2 days. For the OPC, in 2014 the median referral to consultation time was two days and in 2019 it was twelve days.

Figure 1 demonstrates the differential growth of the PCU's services.

The numbers of admissions per year were sixty-five (65) in 2014, one hundred and seventy-five (175) in 2015, one hundred and forty-seven (147) in 2016, one hundred and sixty-five (165) in 2017, one hundred and fifty-seven (157) in 2018, one hundred and seventy-three (173) in 2019 and one hundred and twenty-two (122) in 2020.

OPC numbers quadrupled from one hundred and seventeen (117) in 2014 to four hundred and seventy-one (471) in 2016, plateaued and fell to two hundred and sixty-nine (269) in 2020.

EWMSC consultations rose in consecutive years from one hundred and seventy-three (173) in 2014 to three hundred and ninety (390) in 2018. In 2019 and 2020, numbers of EWMSC consultations fell to two hundred and twenty-six (226) and then to seventy-four (74).

Family meetings numbered fifty-nine (59) in 2016, two hundred and forty (240) in 2017, two hundred and thirty-two (232) in 2018, one hundred and eighty-three (183) in 2019 and one hundred and fifty (150) in 2020.

Telephone encounters increased over the study period, from seventy-nine (79) in 2014 to one thousand, five hundred and seventy-two (1572) in 2020.

Discussion

A major emerging theme was that the Caura PCU serves a predominantly cancer population. The majority of patients referred for admission and to the OPC service and hospital consulting services had cancer. This finding correlates with international trends, which reveal access in favour of cancer patients, with trends showing more frequent and earlier access for patients with cancer compared to those with non-cancer diagnoses.[6,7,8] The commonest cancer diagnoses of PCU inpatients were among the top five cancers reported nationally for men and women in Trinidad and Tobago, but not in the same order. Lung cancer was the commonest cancer among inpatients with almost equal numbers of breast cancer. With prostate cancer the commonest male cancer in Trinidad and Tobago, lung cancer appeared to be over-represented in this sample.[9] The more indolent nature of many prostate cancers, the financial and logistic challenges of obtaining home oxygen for breathless lung cancer sufferers and the PCU's relationship with the nearby National Lung Cancer Unit might be contributors to this finding.

Evidence suggests that the symptom burden of non-cancer patients with advanced disease tends to go unrecognized, yet it can be similar to and sometimes greater than, that of cancer patients.[10,11,12,13] This group has been shown to be sicker, of poorer functional status and in need of more care at the time of palliative care referral.[14,15] There is therefore likely to be a significant unmet need among the non-cancer cohort in Trinidad and Tobago, as it is poorly represented in the PCU's service.

The relatively low numbers of non-cancer referrals may reflect a lack of awareness among referrers of the role of palliative care in non-malignant conditions.[16,17] Between 2014 and 2020, despite an increase in service uptake, there was a reduction in the proportion of non-cancer referrals to OPC and for admission. Targeted approaches may be needed to raise awareness among referring medical specialists.

Patients were frequently referred late in their disease trajectories. This was evident in the short median intervals between consultation and death for patients of the outpatient and hospital consulting services and also in the short length of stay for admitted patients. International studies confirm this trend of late referral,[18-23] as did the only other local study of referrals to a now suspended palliative OPC.[24] The PCU's figures are comparable to those quoted for a tertiary US cancer centre, where the median interval between consultation and death was 1.4 months.[22]

Early palliative care interventions have been shown to be associated with improvements in quality of life and symptom intensity.[25, 26] Late referrals and especially those within hours of death represent a missed opportunity for palliative care interventions to alleviate physical/psychological distress.[22] These missed opportunities might include the chance to put affairs in order, to participate in legacy work, to seek forgiveness and to forgive, all of which contribute to a good death. Multiple factors might contribute to late referrals, among them the misconception that palliative care is only relevant at the end of life.[27-29]

Complex physician factors may also contribute. A recent systematic review found that negative physician emotions impact referral – feelings of abandoning the patient, loss of control, loss of the therapeutic relationship and the loss of hope.[30] Over-prognostication by referring teams may also be a contributor.[31] Work is needed with physicians of different specialties to address the misconceptions and stigma around palliative care referral and to educate on prognostication. The American Society of Clinical Oncology's clinical practice guideline recommends referral to an interdisciplinary palliative care team within eight weeks of diagnosis of an advanced disease.[32] Delivering this standard of care locally will require an intensive education campaign to change attitudes and practice and major service expansion to meet this need.

The PCU data depicted a responsive service, as evidenced by the median intervals between referral and review for the OPC and hospital consulting services. Referral to consultation time remained stable for the hospital consulting service over the years (median interval 1-2 days). For the OPC, the referral to consultation interval increased over the study period, as the number of OPC referrals far exceeded the number of hospital consultation requests, with no increase in size of the medical team. The median referral to consultation time for OPC remained an acceptable seven days.

The PCU's out of hours care for patients in the community was limited to telephone support. Telehealth for palliative home care patients has been shown to be improve access to health professionals and to enable connections and support that foster a sense of security.[33] In the absence of a home care program, the PCU's telephone service represented its only outreach to patients at home. This service provided psychosocial support and remote symptom management, allowing the patient and caregiver to be supported throughout the dying trajectory. The growth seen in the PCU's telephone service over the 6 years was noteworthy. Even prior to Covid-19, this was the PCU's fastest growing service (Figure 1).

The PCU's service and data trends were impacted by the Covid-19 pandemic. While OPC numbers quadrupled between 2014 and 2016, then plateaued until 2019, they fell significantly in 2020, due to the shift to remote care. Uptake of the consulting service at EWMSC showed a similar pattern with annual increases to 2018, then falling to a nadir in 2020. Conversely, steep increases in the numbers of telephone encounters were attributable to the pivot to telehealth necessitated by the pandemic.

This study included all patients accessing care at the PCU, but did not capture the geographic spread of patients served. All RHAs except NCRHA have oncology services, all of which refer to the PCU in the absence of inpatient, outpatient, hospice or palliative care services in most regions. As mentioned, only NWRHA has inpatient hospice beds and no other RHA offers outpatient palliative care. Patients from all these regions access care at the PCU, sometimes far from the informal network of family and friends. Access is most difficult for patients from the sister island of Tobago, who are rarely able to benefit from the PCU's services. Capturing and highlighting data on geographic spread could have helped to justify the need for inpatient and outpatient palliative care services in each RHA.

Study Limitations

While data collection was facilitated by access to the PCU's electronic database, several deficiencies became apparent during data retrieval. Important domains such as coded diagnoses, patient address and source of referral had been overlooked in setting up the database, making this information unavailable for analysis.

Retrieval of admissions data from the paper archive was tedious. Empty data fields and errors in tally were frequently encountered. For inpatient admissions there were sixty-one patients for whom diagnosis was undocumented (Table 2).

With limited IT equipment and no data entry clerk, the completeness and accuracy of the database depended on the recall and conscientiousness of the medical officers entering data at the end of each workday. The database is therefore likely to underrepresent the PCU's work.

These results represent data from a single institution on a small island and may not be representative of other services.

Study Recommendations

An ongoing, nationwide palliative care awareness program should be established, ideally delivered under the umbrella of the Ministry of Health of Trinidad and Tobago and involving all the RHA's. There is a role here for NGO'S such as the Palliative Care Society of Trinidad and Tobago. Internationally, as here in Trinidad and Tobago, faith-based organizations and civil society often act as the catalysts for the establishment of services for the incurably ill. NGOs like the PCSTT can assist in raising public awareness, educating health professionals and in advocacy at the government level, for palliative care.

The Public Health approach to palliative care details the three fundamental pillars upon which palliative care development rests - policy, education and access to medicines.[34] Lacking, is an implemented National Palliative Care Policy for Trinidad and Tobago. Such a policy would describe the nation's vision for Palliative Care development and the strategy including timeline, by which it would be achieved. A draft policy has been submitted to the Ministry of Health, outlining a comprehensive national palliative care service. For each RHA, there needs to be a specialized clinical palliative care team, infrastructure for home-based care, hospital-based care and inpatient palliative care beds. Local and regional training pathways to palliative care specialization would be required to build the necessary capacity to expand services in this way to each RHA. Medical and nursing councils will also need to recognize palliative care as a specialty, to ensure that trained staff can receive due remuneration.

In addition to specialist palliative care services, a palliative approach to care needs to be integrated into Trinidad and Tobago's health system at all levels. It cannot only be the remit of specialist teams like this PCU, which, due to its small size impacts only a fraction of those in need. Continuing education of health professionals into a palliative approach, with modules of palliative care education embedded into undergraduate and postgraduate curricula of medical and nursing schools, will ensure that all health professionals possess basic palliative care competencies.

This paper reviewed an adult palliative care service, but it is as much our ethical duty to provide for children with life limiting illnesses, as it is for adults. There is therefore a need to develop palliative care services for children in Trinidad and Tobago.

Assumptions have been made that the preferences for end-of-life care in Trinidad and Tobago are the same as in other countries. This needs to be explored through research in the local population. While home has been shown to be the preferred place of care and death in many countries, locally, most people die in hospital, with a trend towards increasing hospitalization of death.[35,36,37] Expanding the PCU's service to include home based palliative care and establishing same in other health authorities will require collaboration with primary care services, recruitment and training of physicians and nurses and creation of posts for palliative care leads within each regional health authority. This strategy should be robustly written into the National Palliative Care Policy.

To increase acceptability of palliative care and increase referrals, consideration might be given to embedding palliative care clinics into oncology and other out-patient services. To reduce stigma, some have advocated for a name change from palliative care to supportive care.[30,38] Some evidence suggests that rebranding may be associated with earlier out-patient referrals and more frequent in-patient referrals.[38]

Developing palliative care services will not only benefit patients and families, but evidence suggests that it also has the potential to be cost-effective to health systems.[39,40] Most evidence for the cost savings relates to home-based care,[39] with the general trend towards lower cost being borne out even in low and middle-income countries.[40]

An upgrade of the PCU's infrastructure and systems is needed to facilitate ongoing rigorous research. These include recruitment and assignment of a dedicated data entry clerk to ensure contemporaneous data entry, a move from the written admissions ledger to a computerized database and modification of the existing electronic database to include additional domains such as coded diagnosis, telehealth consults, patient home address and source of referral.

Conclusion

This paper describes the work of a single palliative care service in a resource limited setting. The Caura PCU provides a responsive service, predominantly to patients with cancer diagnoses, the majority of whom are referred late in their disease trajectory. There is need to raise awareness of the benefits of early palliative care referral for patients with all life-limiting diagnoses and to expand palliative care services to all regions of Trinidad and Tobago.

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