A Descriptive Study On The Introduction of a Palliative Care Unit at an Oncological Facility in the Caribbean.

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ABSTRACT:

BACKGROUND:
Palliative care is a currently undeveloped area with close affiliation to oncology, and its importance is often understated. Early integration is essential but limited in developing countries.

OBJECTIVES:
To outline unmet needs and emphasize benefits derived from the introduction of a palliative care unit at the main Oncology facility in the country.

METHODS:
Patient records from the palliative care unit during six months were retrieved manually. Patients needed to have a confirmed malignancy and advanced-stage disease to be included in the review.

RESULTS:
A total of 73 patients resulted in 162 visits. Gastrointestinal malignancies required the most input. Patients were predominantly female (58%), and the median age was 68 years. Most patients were referred late (more than eight weeks) after diagnosis of advanced-stage disease, with an Eastern Cooperative Oncology Group (ECOG) of three or more, and had a prognosis of fewer than three months. The median number of visits per patient was two, while the mode was one. Only 9.3% of patients required hospital admission. The majority of patients (72.6%) were referred after all treatment options were exhausted, and referrals from the palliative care unit were most commonly for hospice support.

CONCLUSION:
This introductory experience with a palliative unit outlined key areas for improvement. These included the need for earlier referrals to aid in the timely initiation of interventions addressing end of life care decisions.
This has the potential to reduce the financial and low human resource burdens faced by our healthcare system.

INTRODUCTION:

Palliative Care, as defined by the World Health Organization (W.H.O.), is an approach geared towards improvement in the quality of life of patients and their families facing problems associated with life-threatening illnesses. It achieves this through early identification, assessment, and treatment of pain and other problems: physical, psychological, social, and spiritual [1].

Patient screening programs are often limited in developing countries as a result of resource constraints, and consequently, these countries often have to manage a more significant proportion of patients with advanced-stage disease due to late diagnoses. Additionally, delivery of healthcare is often sub-optimal and unevenly distributed, with some analgesic medications not being widely available and cultural belief systems and preferences sometimes acting as barriers that further limit access to measures geared at symptom control in terminal illness [2].

According to the Pan American Health Organization (P.A.H.O.) report in 2018, cancer was the second leading cause of death in the Americas. It was responsible for 1.3 million deaths and 3.7 million new cases (accounting for 21% of the cases globally). The same study noted a projected increase to five million new cases by 2030, due to the aging of the population and the epidemiological transition in Latin America and the Caribbean [3]. Data from Trinidad and Tobago showed that between 1995 and 2009, there were a total of 29,512 incident primary cancers, and 18,216 cancer deaths, with an overall case-fatality rate of 61.7% [4].

Multiple studies indicate that integrating palliative care early in the disease trajectory can result in improvements in quality of life, symptom control, patient and caregiver satisfaction, quality of end-of-life care, survival, and costs of care [5, 6]. There have been limited studies in the Caribbean providing information that supports the need to establish a care unit or program devoted to palliative care at an oncological facility where patients are seen at all stages in the trajectory of their illnesses.

The National Radiotherapy Centre (N.R.C.) in Trinidad and Tobago was founded in the early 1970’s and for approximately two decades, was the sole facility for adult medical and radiation oncology services in the public sector. It is the main facility for medical oncology and is the only institution offering radiation oncology for public patients. To date, it continues to offer services to the most substantial proportion of these patients for both public and private care. The first state-funded palliative care unit in the Caribbean was the Caura Hospital Palliative Care Unit in Trinidad and Tobago which was opened in August, 2014. It is a twelve-bed inpatient unit serving patients in the end stages of their life-limiting illnesses [7]. In July 2015, a regular and consistent palliative care unit was introduced at the NRC in Trinidad and Tobago. The introduction of a palliative care unit was geared at assessing the palliative care needs of the facility and developing an understanding of palliative care culture.

We aimed to explore and highlight the benefits gained from the introduction of the service at the National Radiotherapy Centre in Trinidad and Tobago.

MATERIALS AND METHODS:

Study Setting
This descriptive study was undertaken to assess multiple parameters associated with palliative care delivery, including patient characteristics, patient load, timeliness of referrals, frequency of visits, and supportive services.

The study period covered January 1st 2016 to June 30th 2016. During that period, the unit consisted of two junior doctors, a consultant in palliative care, and a specialty nurse. The unit operated a clinic once a week with on-site consultant coverage. On other days, referrals were discussed with the consultant and either booked for review at the next clinic or admitted immediately in cases where prompt attention was required through collaboration with the treating oncologist. Patient referrals came from the Medical Oncology Clinic.

**Study Design**

Retrospective longitudinal and descriptive study.

**Data Collection Methods**

Data were obtained from patient records. Parameters associated with palliative care delivery were assessed as per documentation during the study period. Patients needed to be over the age of 18 and diagnosed with malignancy to be included. Patient performance status was grouped using the Eastern Cooperative Oncology Group (ECOG) grading system. This scoring system was published by Oken et al. in 1982, which uses a scale of 0 to 5 [8]. The ECOG score is often preferred for its simplicity and intra-observer reproducibility [9].

**Data Analysis**

Demographic data and parameters associated with palliative care were tabulated using Microsoft ® Excel 2010 (Microsoft, Redmond, WA.).

**RESULTS:**

During the study, a total of 73 patients were seen, resulting in 162 clinic visits.

**Patient demographics**

Patient demographics, including diagnoses grouped by disease type and site are presented in table 1.

**Table 1. Demographics for Palliative Care Unit patients, grouped by Cancer site and Performance Status**

| Age          | Male | %  | Female | %  | Total | %  |
|--------------|------|----|--------|----|-------|----|
| N= 31        | 42   |    | N=42   | 58 | N=73  | 100|
| Range        | 40-89|    | 35-82  |    | 35-89 |    |
| Mean         | 65.87|    | 63.38  |    | 64.43 |    |
| Median       | 67   |    | 68     |    | 68    |    |
| Malignancy   |      |    |        |    |       |    |
| Gastrointestinal | 11   | 36 | 13     | 31 | 24    | 33 |

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Performance status is also demonstrated and was scored utilizing the ECOG scale. The top four cancer groupings were gastrointestinal (33%), genitourinary (19%), breast (15%) and gynaecological (14%). In three cases (4.1%) the primary cancer was undocumented.

**Time from diagnosis to referral**

Table 2 shows the time from the diagnosis of metastases to referral to palliative care and estimated prognosis. There were 15 (20.5%) patients for whom the time frame for a referral to the palliative care unit could not be assessed due to missing data. However, the majority of patients (50.7%) were not referred within eight weeks of having been diagnosed with advanced-stage disease. The majority of patients, 38 (52.1%), had an estimated prognosis of less than three months. In approximately 20% of patients, life expectancy was not stated, while only 2.7% had a life expectancy of greater than one year.

**Table 2. Time to referral to Palliative Care Unit after diagnosis of metastases and estimated prognosis**

| Time from diagnosis of metastases to referral to Palliative Care | Total | %  |
|---------------------------------------------------------------|-------|----|
| N=73                                                          |       | 100|
| Within 1 week                                                 | 7     | 9.6|
| >1 week - 8 weeks                                             | 14    | 19.2|
| >8 weeks - 1 year                                             | 23    | 31.5|
| >1 year                                                       | 14    | 19.2|
| Not stated                                                    | 15    | 20.5|

**Estimated Prognosis**
Frequency of visits, discussions on advanced care directives and religious affiliation

The frequency of patient visits, advanced care directive discussions and patient admission of religious affiliation are presented in Table 3. There were 162 patient visits across the 73 patients. The majority of patients had only one visit (39.7%) while the median number of visits was two. In 37% of the cases, patients had three or more visits to the unit for symptom control. Pain was the most common symptom managed. Most patients (64.4%) admitted to being involved in a particular religion. Only 32.9% were not engaged in religious practice. In discussions on advanced care directives (ACD), 63% of patients were introduced to conversations on the same. All patients disclosed that ACD had never been discussed with them prior.

Table 3. Patient visits and records discussions on religious involvement and advanced care directives

| Frequency of visits | No. of patients | Percentage of total patients | Total number of visits | Percentage of total visits |
|---------------------|-----------------|------------------------------|------------------------|----------------------------|
| Total = 162         |                 |                              |                        |                            |
| Median = 2          |                 |                              |                        |                            |
| 1                   | 29              | 39.7                         | 29                     | 17.9                       |
| 2                   | 17              | 23.3                         | 34                     | 21.0                       |
| 3                   | 14              | 19.2                         | 42                     | 25.9                       |
| 4                   | 11              | 15.0                         | 44                     | 27.2                       |
| 5                   | 0               | 0                            | 0                      | 0                          |
| 6                   | 1               | 1.4                          | 6                      | 3.7                        |
| 7                   | 1               | 1.4                          | 7                      | 4.3                        |

Advanced Care Directive

| Yes     | 46 | 63.0 | -   | -   |
| No      | 27 | 37.0 | -   | -   |

Religious affiliation

| Yes practising | 47 | 64.4 | -   | -   |

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Frequency of referrals to other services

The majority of patients (63%) did not need an external referral to allied areas or specialties, and their issues were managed in-house (table 4). Hospice referral was the most common referral (13.7%), with referrals back to oncology being the third most common in 9.6% of cases.

Table 4. Types of Referrals made from Palliative Care Unit to other Hospital Services

| Referrals from the Palliative Care Unit | Frequency | Percentage |
|----------------------------------------|-----------|------------|
| Dietician                              | 2         | 2.7        |
| Hospice                                | 10        | 13.7       |
| Oncologist                             | 7         | 9.6        |
| Social Worker                          | 2         | 2.7        |
| Specialty Outpatient Clinic            | 4         | 5.5        |
| Tertiary Acute Care In-patient Facility| 2         | 2.7        |
| Nil                                    | 46        | 63.0       |

Oncological treatment at the time of referral to palliative care clinic

The oncological therapeutic management which patients were receiving at the time of referral was also recorded (Table 5). Less than 27.4% of patients were on active treatment. These treatments varied, with the most prevalent being chemotherapy (15.1%), followed by radiation therapy and hormonal therapy (each 4.1%). Other treatment modalities accounted for 2.7% of interventions. The most significant proportion of patients (72.6%) were not receiving any treatment.

Table 5. Oncological Treatment Interventions at the time of referral to Palliative Care Unit

| Current Oncological Treatment | Number of Patients | Percentage |
|-------------------------------|--------------------|------------|
| Chemotherapy                  | 11                 | 15.1       |
| Chemotherapy and Radiotherapy | 1                  | 1.4        |
| Radiotherapy                  | 3                  | 4.1        |
| Targeted Therapy (Hormonal)   | 3                  | 4.1        |
| Targeted Therapy (Immunotherapy) | 2                | 2.7        |
| Nil Active Treatment          | 53                 | 72.6       |
| Total                         | 73                 | 100        |

DISCUSSION
The Caribbean Palliative Care Society was developed to advocate for improved patient access to palliative care services [10]. The data on their website identifies dedicated palliative care units or institutions in five countries, namely Barbados, Belize, Cayman Islands, Jamaica, and Trinidad and Tobago. Though Trinidad and Tobago and Jamaica are the two of the largest populated islands, the ratio of population size to the palliative care unit was significantly less than that observed in the less populated island countries [10].

The Palliative Care Unit at the National Radiotherapy Centre received a total of 73 patient referrals for the period January 1st- June 30th, 2016. Though a small sample size, the data mirrored that of the Global Cancer Observatory (Globocan) 2018 Statistics for Trinidad and Tobago where the top four malignancies were Gastro-intestinal, Genitourinary, Breast, and Gynaecological Cancers [11]. Patients were more likely to be female and younger compared to males, and the median age was almost the same for both genders (Table 1).

The American Society of Clinical Oncology guidelines indicates that palliative care should be instituted within eight weeks of being newly diagnosed with advanced cancer [7]. In this study, only 28.8% of patients were seen within eight weeks of diagnosed metastatic disease compared to the majority of patients who were referred later, which is not an uncommon practice [12]. This situation may be attributed to a multitude of factors inclusive of inadequate education and training of allied health care staff as well as improper techniques necessary in dealing with the process of dying [13]. As such, rationing of early referral may ultimately occur due to a lack of understanding of a time-sensitive process [14]. Additionally, the lack of awareness of the service itself due to the short time from its introduction for the sampled period could have contributed to late referrals.

Thirty-eight (52.1%) patients had a life expectancy of fewer than three months. Delays in referrals have prompted many studies to demonstrate the benefit of integrating palliative care early and alongside standard oncologic care [15]. Patient’s longevity in the palliative care unit through earlier referrals, along with targeted guidance from experienced palliative care clinicians has the potential to offer many benefits to the patient and their caretakers. One of these benefits is a reduction in hospital re-admissions and the length of the hospital stay. Glasgow and colleagues proposed that once clear lines of communication are established between the patient and the clinician concerning the patient’s prognosis and goals, a consequential reduction in admission rates can be noted [16]. Another benefit is reduced economic burden, as seen in two studies that showed the projected costs for acute medical care were higher in patients who never received a palliative care consultation [17, 18]. This reduction in the price of care can be helpful in a health care system that is burdened with large patient numbers such as ours.

In this study, there were a total of 162 patient visits. The majority of patients had only one visit during that time. Most visits were scheduled appointments based on referrals and follow-up visits. There were only 15 occasions that resulted in hospital admissions. The total number of patients who required consultation above two visits was 27, and these accounted for 37% of all visits with pain being the most common symptom requiring management. During that period, morphine (the primary opiate based analgesia available) was in short supply, and thus admissions may have been associated with this restriction.

In a clinical setting, the focus is usually placed solely on the patient’s clinical symptoms. However, palliative care incorporates other areas which also notably influence the patient’s well-being and thus supports holistic care. The integration of psychological and spiritual aspects into patient care while also assessing patient social support mechanisms is essential. In the current study, sixty-seven percent of patients admitted to a religious affiliation with the majority (64.4%) actively practicing their faith. In most patients, spirituality was discussed. Coping mechanisms associated with religion or spirituality have been shown to affect the quality of life
positively. Therefore, addressing these early can favorably influence the continuum of palliative care [19, 20].

Apart from symptom assessment, psychological and spiritual aspects, another domain of palliative care includes daily functioning which was assessed with the Eastern Cooperative Oncology Group (ECOG) scoring system. Most of the patients in this study had limited capacity of daily functioning likely due to late referral but may also be due to other confounding factors such as aggressive disease, refusal of treatment or no feasible treatment option available to offer.

Advanced care directives were also discussed with patients and their families. These discussions were introductory in our population, which does not have the familiarity with the practice of the same. Responses were varied, with many patients preferring to leave the decision to the discretion of their family or other loved ones. Many verbalized the wish to die at home and not in the hospital. A systematic review done by Finlayson et al. found that when patients were aware of their advanced disease status, they were usually disinclined to pursue measures that could extend their life span if this meant that their quality of life would be adversely affected [21]. In almost all instances after a thorough explanation of their diagnosis, prognosis, and potential treatment options, patients in the systematic review made a personal choice to opt for palliative care rather than life-extending treatment, which could be potentially distressing [21]. However, other factors that can potentially contribute to this phenomenon include prohibitive cost or side effect profile of treatment, ineffective, limited or untested treatment, and poor prognosis. Unfortunately, in many cases, patients with advanced or terminal cancer are not fully aware of their prognosis, as described in the meta-regression analysis by Chen et al [22]. Thus, the inclusion of these discussions in their care pathway has the potential to preserve the quality of life and also reduce costs associated with additional procedures or medication of limited benefit.

In cases where patients required additional assistance than could be offered by the palliative care unit, they were referred elsewhere. The most common referrals were to hospice (13.7%). Only 9.6% of patients required direct intervention from the referring oncologist, which included palliative chemotherapy, radiotherapy or acute management for oncology treatment-related events. While out-patient referrals to other specialty clinics were needed in 5.5% of cases, in-patient acute care referrals were warranted in only 2.7% of cases. The palliative care unit thus may have a role in reducing the patient load on the general oncology clinic by managing patient symptoms and related care issues. This would otherwise be added to the duties of the oncology unit. This load sharing is of particular importance in settings like the Caribbean, including Trinidad and Tobago, where oncology staff is deficient [23].

Some patients were receiving various oncological treatments at the time of referral. Most of the patients referred seemed to have exhausted other treatment options. This tendency to refer patients only at the end of their oncological treatment pathway is not uncommon. In a study by Johnson et al., oncologists admitted to late referrals, and these were only prompted by uncontrolled physical symptoms or disease that was imminently terminal [24]. In some studies, it has been reported that palliative care physicians were less inclined to accept patients who were still on active treatment, such as chemotherapy [25, 26]. Thus, clear guidelines for referral should be outlined by these palliative care units to aid not only timely but also appropriate referrals.

Hui et al. published a comprehensive paper proposing essential eligibility criteria for such referrals [27]. Eleven major criteria for referral included severe physical symptoms, severe emotional symptoms, request for hastened death, spiritual or existential crisis, decision making or care planning aid, patient request, delirium, spinal cord compression, metastases to brain or leptomeninges, within three months of advanced cancer
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diagnosis for patients with median survival of one year or less, and progressive disease despite second-line therapy. Some of these criteria were intuitively applied but were not formally utilized. They could be beneficial in our setting as we aim to build on the service. These services can be further expanded through the support of specialty nursing, and efforts to equip the nursing fraternity to meet the growing demand are critical to enhancing holistic care [28].

CONCLUSION

This brief introduction of the palliative care unit identified multiple gaps in the continuum of care which we can offer our patients. Early collaboration between oncology and a dedicated palliative care unit has the potential to offer significant benefits to our patients. An appreciation of the need to commence palliative care intervention early in the course of management of the patient with advanced cancer is crucial.

The program initiated at the center may ultimately help to reduce the burden on the oncology clinic. Additionally, initiating palliative care programs has the potential to reduce costs associated with care for the patient who succumbs to progressive symptoms at the end of life. It can facilitate this through the reduction in hospital admissions, fostering home-based care and the initiation and acceptance of advanced care directive plans. More importantly, these measures have been linked to an improvement in patient’s quality of life through thorough assessments of goals of care, patient autonomy, and the avoidance of futile medical interventions. However, trained specialists are few, and while there is proven potential for cost savings for Governments in the implementation of these programs, the absence of staff specially trained in the field is an obstacle to its development.

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