

# Palliative care and end-of-life measure outcomes: Experience of a tertiary care institute from South India

Praveen Adusumilli, Lingaraj Nayak, Vidya Viswanath<sup>1</sup>, Leela Digumarti<sup>2</sup>, Raghunadha Rao Digumarti

## Abstract

**Introduction:** Desisting from disease directed treatment in the past weeks of life is a quality criterion in oncology service. Patients with advanced cancer have unrealistic expectations from chemotherapy and hold on to it as a great source of hope. Many oncologists continue futile and unnecessary treatments, instead of conveying to the patients the lack of benefit, resulting in delayed referral for palliative care (PC). **Materials and Methods:** This is a retrospective analysis of case records from June 2014 to December 2015. The primary objective was to study, how far back in time terminally ill cancer patients received definitive cancer directed therapy (DCDT). Apart from patient demographics, the diagnosis, stage, and details of DCDT, and death were captured. PC referral data were recorded. DCDT to death was taken as treatment-free interval (TFI). Analysis was performed using IBM SPSS Statistics for Windows, Version 20. **Results:** A total of 292 case records were evaluated. Seventy-three had inadequate treatment details. Hence, 219 records were analyzed. PC referral was done in 78.5% of patients. Only best supportive care (BSC) without any DCDT was given in 27 patients. The most common reason for BSC was a poor performance status in 92.5%. The median time from PC referral till death was 43.5 days (range: 1–518 days). Chemotherapy was the most common DCDT in 52.9% of patients. The median time from DCDT and death was 49 days (range: 0–359 days). Cervical and ovarian cancers patients had the longest TFI; shortest in unknown primary. Most patients died at home (70.4%). Patients receiving PC preferred home or hospice as place of death. Of the 80 patients given hospice care, 39 (36.5%) died in the hospice. **Conclusion:** While DCDT needs to be started at the right time, it should also be discontinued when futile. Early involvement of the PC team, even while patients are on DCDT makes the transition smoother and more meaningful.

**Key words:** End-of-Life measures, palliative care, South India, tertiary institute

## Introduction

Palliative care (PC) is patient and family centered care that optimizes quality of life (QOL) by anticipating, preventing, and treating suffering. PC throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.<sup>[1]</sup> PC is considered a human right to health.<sup>[2]</sup> Each year, while an estimated 40 million people are in need of PC, 78% of them live in low- and middle-income countries. Indeed, 98% of children needing PC live in low- and middle-income countries.<sup>[3]</sup>

India has a high load of cancer and it is rising. In 2015, the incidence of cancer in the country was estimated to be 1,148,691, which is likely to go up to 1,320,928 cases by the year 2020.<sup>[4,5]</sup> A number of major barriers exist in the efforts to meet the needs for PC, such as national health policies, health-care systems which do not often include PC services and training on PC for health professionals.<sup>[6,7]</sup> Even though the concept of PC exists for many decades, it has come in to limelight again after the advent of 2012 American Society of Clinical Oncology provisional clinical opinion on the integration of PC in to standard oncology care and transition the content in to a guideline.<sup>[8]</sup> Early PC referral in an outpatient setting provides room for longer therapeutic relationship, discussion of goals of care, and advanced care planning, which could facilitate improved end-of-life (EOL) care outcomes.<sup>[9]</sup>

Desisting from disease directed treatment in the past weeks of life is a quality criteria of oncology service. Many oncologists choose to continue futile and unnecessary treatments, instead of conveying to the patients that there are no benefits to maintaining the anticancer treatment.<sup>[10]</sup> Various retrospective studies have reported active treatment rates in the past 4 weeks of life

ranging from 23% to 55.6%.<sup>[11-14]</sup> Patients with advanced cancer have unrealistic expectations regarding the treatment and hold on to chemotherapy as a great source of hope.<sup>[15-17]</sup> Due to this a large proportion of 30%–50% patients die in the hospital, which is in about 25% of cases due to the harmful effects of chemotherapy which brings terminal cancer patients into such a state that they cannot be discharged from hospital.<sup>[18]</sup> Furthermore, patients with metastatic cancer, who receive early PC, are most likely have better perception of their prognosis. This facilitates the understanding of the real benefits of new types of anticancer treatment.<sup>[19]</sup>

## Materials and Methods

This is a retrospective analysis of case records from June 2014 to December 2015. The primary objective is to study, as a measure of PC, how far back in time did a terminally ill cancer patient receive definitive cancer directed therapy. The duration of such treatment was recorded in days/weeks/months.

Data were captured in a preformatted recording. Apart from patient demographics, the diagnosis, stage, and details of any Definitive Cancer Directed Treatment (DCDT), along with death were captured.

Data on referral to PC was recorded. The date of last definitive cancer directed treatment was used for calculate the treatment free interval (TFI) up to death as it was used as a measure of individual physicians futility of definitive treatment and utility of PC.

Palliative treatment like radiation to painful bony metastases and impending fracture were captured. Similarly, radiation for brain metastases with features of increased intra cranial pressure was taken as a life saving measure and not definitive treatment.

Frequencies and percentages were calculated for overall descriptive statistics. To compare the improvement using

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Departments of Medical Oncology, <sup>1</sup>Palliative Medicine and <sup>2</sup>Gynaec Oncology, Homi Bhabha Cancer Hospital and Research Centre, Aganampudi, Andhra Pradesh, India

**Correspondence to:** Dr. Praveen Adusumilli, E-mail: praveen.adusumilli@yahoo.com

nominal data, Chi-square test was used. Analysis was performed using IBM Statistical Package for the Social Sciences version 20 (IBM Corp. Released 2011. IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.).

## Results

A total of 292 case records were evaluated. Seventy-three case records had inadequate treatment details. Hence, 219 case records were analyzed.

The baseline demographic and PC characteristics are depicted in Table 1. PC referral was done in 78.5% of patients. Only best supportive care (BSC) and no DCDT was given for 27 patients. The most common reason for BSC was poor performance status in 92.5% of patients. The median time from PC referral till death was 43.5 days (range: 1–518 days).

The last definitive treatment details are depicted in Table 2. Chemotherapy was the most common last definitive treatment given in 52.9% of patients. The median time from last definitive treatment given and death was 49 days (range: 0–359 days).

The incidence of various cancers and median TFI between last definitive treatment and death in various cancers according to the site of cancer is depicted in Table 3. Cervical and ovarian cancers patients had the longest TFI and patients with malignancy of undefined primary origin the shortest.

Most patients died at home (70.4%). Patients receiving PC preferred home or hospice as place of death. Of the 80 (36.5%) patients given hospice care, 39 died in the hospice.

## Discussion

The availability of a PC Medicine Department in our institute, along with hospice and home care is perhaps the reason for early PC referrals (78%).

Rugno *et al.*<sup>[20]</sup> reported that patients who were not previously evaluated in PC received more chemotherapy in the past 6 weeks of life compared to those who had already been evaluated (40% vs. 5.9%,  $P = 0.001$ ) and survived longer (although statistically not significant). Temel *et al.*<sup>[21]</sup> in a Phase III randomized controlled trial (RCT) of patients with newly diagnosed nonsmall cell lung cancer (NSCLC) compared early PC with standard care in an outpatient setting. Patients in the intervention arm had higher QOL, less aggressive EOL care, lower rates of depression and longer survival by 2.7 months.

The median TFI before death in our study of 49 days (range: 0–359 days), is more when compared to study by Braga *et al.*<sup>[12]</sup> A study from Earle *et al.*<sup>[22]</sup> showed that the TFI before death varied from 65 to 71 days. Some characteristics predictive of an increase in the chances of a patient receiving chemotherapy in the past month of life are: a young woman, a chemo-responsive tumor and a small oncology service.<sup>[23]</sup>

The median time of 43.5 days (range: 1–518 days) between PC referral and death in our study is similar to that reported by Cheng *et al.*<sup>[24]</sup> Time from PC consultation to death also decreased from 33 in 2003 to 11.5 days in 2008 over the 5-year span in a study from Mayo Clinic.<sup>[25]</sup> A delay in PC referral not only shortens the possibility for building rapport and providing meaningful relief of symptoms but also provides less opportunity for cost savings. Lowery *et al.*<sup>[26]</sup> studied the cost saving benefit and health-care utilization in platinum

**Table 1: Baseline characteristics**

	<i>n</i> (%)
Male	107 (48.9)
Female	112 (51.1)
Palliative care referral	172 (78.5)
No palliative care referral	47 (21.5)
Hospice admission	79 (36.1)
No hospice admission	140 (63.9)
Place of death	
Home	154 (70.4)
Hospital	26 (11.9)
Hospice	39 (17.8)

**Table 2: Details of the last definitive treatment given**

	<i>n</i>	Median TFI in days (95% CI)
Chemotherapy	116	50 (58-81)
Targeted therapy	56	34 (37-72)
Metronomic therapy	14	30 (25-72)
Radiotherapy	5	58 (28-97)
No treatment received	28	53 (47-114)

TFI=Treatment-free interval, CI=Confidence interval

**Table 3: Median treatment-free interval according to disease site**

Disease site	<i>n</i>	Median TFI in days (95% CI)
Head and neck	30	69.5 (55-128)
Breast	29	29 (28-62)
Lung	26	44 (35-67)
Cervix	13	121 (68-142)
Ovary	6	92.5 (8-187)
Colorectal	15	52 (38-80)
Pancreaticobiliary	20	38 (35-73)
Hepatocellular carcinoma	9	30 (4-86)
Gastric cancer	25	55 (45-94)
Renal cell carcinoma	6	32 (13-54)
Prostate cancer	2	72 (69-83)
Urinary bladder	1	-
Bone cancers	6	34.5 (25-82)
Acute leukemia	2	60 (16-104)
Chronic leukemia	8	37.5 (10-81)
Lymphoma	8	30.5 (11-90)
Pediatric cancers	2	24.5 (21-94)
Metastases of unknown origin	2	19 (6-44)
Miscellaneous	9	108 (57-124)

TFI=Treatment-free interval, CI=Confidence interval

resistant ovarian cancer. In this study, it was seen that early PC was associated with cost savings of \$1285 per patient over routine care. Temel *et al.* reported from an RCT in NSCLC that in patients receiving early specialist PC intervention, a higher proportion were aware that their disease was not curable at 12 weeks. Furthermore, patients in the early PC group had better awareness that the goal of cancer treatment was not cure. Patients who had better illness perception and better awareness of goals of treatment received less intravenous chemotherapy toward EOL.<sup>[27]</sup> Various studies by Ghoshal *et al.*<sup>[28]</sup> and McCaffrey *et al.*<sup>[29]</sup> focused on the economic challenges of palliative and EOL care.

The ENABLE II study randomly assigned patients with advanced cancer to an advanced practice nursing PC

intervention versus usual care. It found a higher QOL and lower depressed mood with the intervention.<sup>[30]</sup> The ENABLE III study of Bakitas *et al.*<sup>[31]</sup> also compared early versus delayed PC in both solid tumors and hematological malignancies and concluded that there is improvement in QOL and 1 year survival without significant benefit in overall survival. The oncologists, nurses, and patients perspectives on integration of early specialist PC from India is studied by Salins *et al.*<sup>[32]</sup>

The last definitive treatment given in our study was chemotherapy in 53% of patients. Similar to our study, in a systematic review by Luta *et al.*,<sup>[33]</sup> chemotherapy is most frequently reported “life prolonging treatment” at EOL. A study by Rochidneux *et al.*<sup>[34]</sup> stated 39% of patients with metastatic solid tumors received chemotherapy in the past 3 months of life.

Place of death is one of the quality markers for the care at EOL.<sup>[35]</sup> Thirty-six percent of patients had hospice care at some point of time in their PC and 17% of patients died in the hospice. In a study by Mack *et al.*<sup>[36]</sup> among adolescents and young adults, 23% of patients were in hospice care before death, with the first enrolment at a median of 20 days (range: 8–45 days) before death. Similar to a study by Paris *et al.*<sup>[37]</sup> most of our patients receiving PC died at home.

## Conclusion

While the decision to implement DCDT in time is as important in cancer therapy, it is equally imperative to relinquish futile treatments for cancer while continuing PC. Early involvement of the PC team, even while patients are on DCDT makes the transition smoother, more meaningful and goal setting. The recognized lack of optimum prognostic tools and the acknowledged optimism of oncologists favor the institution of unnecessary “super-treatments.” When receiving chemotherapy, patients with tumors with a low chance of responding to treatment and/or with borderline or inadequate functional performance will most likely experience an iatrogenic decrease in their life expectancy.

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## Conflicts of interest

There are no conflicts of interest.

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