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A retrospective study on the state of palliative care in the city of Amritsar

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Abstract

Introduction: Palliative care is an approach that improves the quality of life of patients through the prevention and relief of suffering by means of early identification and treatment of pain and other problems with narcotics like Morphine and other controlled substances for pain.

Methods: In the present study, we have conducted a retrospective study on 1762 terminal stage cancer patients admitted in two hospitals at Amritsar and evaluated the pain management of the patients that reflects upon the palliative outcome of the patients. The primary aim of our study was to evaluate chronic pain management in stage III and IV cancer patients and the assessment of the adequacy of pain management using Pain management index. Raw data was collected in a Microsoft excel sheet and analyzed. Number of patients and percentages of cases were analyzed using Chi square tests and independent t -test. Results: In our study, the maximum number of patients had a pain management index score of -1 (897 patients out of 1762; 50.9%) showing inadequate pain management. This was followed by a pain management index score of zero that was recorded in 742 patients amounting to 42.11% of the total patients.

Discussion: In our study, the retrospective analysis of terminal cancer patients was done and all the patients received radiotherapy as a treatment or palliative care. The pain management regime of the patient was noted and analyzed as the palliative outcome score. The most common type of cancer in females was Carcinoma breast which accounted for 42.06% of the total cases in female population in study followed by Carcinoma cervix that accounted to 18.84% of the total cases. However, in males the most common type of cancer was carcinoma lung that constituted of 11.25% of the total cases followed by Ca larynx (9.42%).

Keywords: palliative care, treatment of pain, cancer patients

Introduction

Palliative care, also called *comfort care*, supportive care or *symptom management* [1], is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual [2]. The concept of palliative care is relatively new to India, having been introduced only in the mid-1980s. Since then, hospice and palliative care services have developed through the efforts of committed individuals, including Indian health professionals as well as volunteers, in collaboration with international organizations and individuals from other countries [3].

According to Indian Association of Palliative Care (IAPC), Palliative care access is very limited across India with exception to a few places. Furthermore, access to Morphine and other controlled substances for pain and symptom relief is also extremely limited. Public awareness on End of life care (EOLC) is non-existent and the health care providers have limited knowledge on EOLC provision and only a few centers have the infrastructure to support the same. The IAPC also lists additional barriers to EOLC, including but not limited to lack of knowledge, treating patients acutely and inappropriately, economic incentives, lack of national/ institutional policy, prevalent social and cultural norms, social acceptance, non-acceptance of this concept and constant search for cure by the family [4]. Palliative care was born in India as the Shanti Avedna Sadan in Mumbai, a hospice, in 1986[5]. Over the next five years, it established two more branches, one in Delhi and one in Goa; but patients outside these institutions had no access to palliative care. Two major developments occurred in the 1990s. One was the formation of the Pain and Palliative Care Society (PPCS) in Calicut in the South Indian state of Kerala in 1993. The other was the formation of the Indian Association of Palliative Care in 1994 [6]. Despite that, Economic intelligence unit report on Quality of Death 2010 reported that India is the worst place to die (ranking 40 out of the 40 countries studied) [4]. This raises serious concerns about the lack of palliative care in India.

In recent years, a few of the major barriers have begun to be overcome. The South Indian state of Kerala, which has 3% of India's population, stands out in terms of achieving coverage of palliative care. This has been achieved initially by non-government charitable activity, which catalyzed the creation of a government palliative care policy. On the national level, recent years saw several improvements, including the creation of a National Program for Palliative Care (NPPC) by the government of India in 2012. The year 2014 saw the landmark action by the Indian Parliament, which amended India's infamous Narcotic Drugs and Psychotropic Substances Act, thus overcoming many of the legal barriers to opioid access. Education of professionals and public awareness are now seen to be the greatest needs for improving access to palliative care in India [6].

In the present study, we have conducted a retrospective study on 1762 terminal stage cancer patients admitted in the radiotherapy unit of Government Medical College Amritsar and Sri Guru Ramdas Institute of Medical sciences and evaluated the pain management of the patients that reflects upon the palliative outcome of the patients. The primary aim of our study was to evaluate chronic pain management in stage III and IV cancer patients and the assessment of the adequacy of pain management using Pain management index.

The secondary aim was to discuss the need for adequate palliative treatment and evaluate the factors that need to be looked into for its implementation.

Material and Methods

After approval from the Institutional Ethical committee, a retrospective non-interventional study was conducted in the department of Anesthesia and Critical Care in association with the Radiotherapy department of Government Medical College, Amritsar.

1762 patients diagnosed with terminal cancer and who received radiotherapy and chemotherapy at GMC Amritsar and SGRD medical college in Amritsar from July 2015 till June 2017 were included. The medical record of the patients included will be obtained from the respective centres and the following data were noted:

- Demographic profile including the age, gender, height, weight, marital status and occupation of the patient.
- Diagnosis
- Family history
- Cancer categories/type
- Ongoing Treatment:
  - Cancer related treatment
    - Surgery
    - Chemotherapy
    - Radiotherapy
  - Palliative treatment and pain management
    - Radiotherapy
    - Oral/intravenous drugs
    - Transdermal patches
    - Psychological therapy/ rehabilitation
    - Regional blocks
      - ✓ Pain management index.
      - ✓ Availability of terminal care providers/ trained staff

The data was systematically collected, compiled and statistically analyzed to draw relevant conclusion. The pain management index was taken as a performance marker of the palliative care. For calculating the PMI [7, 8], treatment was rated on a four-point scale as follows: 0- no analgesia, 1- nonopioid analgesic, 2- ''weak'' opioid, 3- ''strong'' opioid. The PMI is calculated by subtracting the POS score from the analgesic treatment level, which results in a score ranging from 3 (severe pain in a patient on no analgesia) to -3 (no pain in a patient on strong opioids). Negative scores indicated inadequate pain management; positive scores or zero described a conservative indicator of acceptable treatment. The POS score or the patient outcome score was a 4-point grading of pain according to the patient i.e. 0- no pain, 1- mild pain, 2- moderate pain, 3 severe pain which was noted according to the patient's complaints in the history.

Statistical Analysis

Raw data was collected in a Microsoft excel sheet and analyzed using Statistical package for the social sciences (SPSS) version 22.0. Number of patients and percentages of cases expressed discrete categorical data and were analyzed using Chi square tests and independent t-test.

Results

The total number of patients were 1762, out of which 711 were males and 1051 were females. On comparing the marital status of the patients 84.5% were married, 1.31% were unmarried and 7.92% were widower/ widow and 0.11% were divorced. (Table 1 and 2).

Table 1: Occupation * Sex

Occupation	Sex				Total	
	Male		Female		No.	%
	No.	%	No.	%		
Unemployed	267	37.55	869	82.68	1136	64.47
Unskilled	227	31.93	74	7.04	301	17.08
Semi-Skilled	63	8.86	44	4.19	107	6.07
Clerical/shop/farmer	136	19.13	57	5.42	193	10.95
semiprofessional	18	2.53	7	0.67	25	1.42
Total	711	100.00	1051	100.00	1762	100.00

X^2: 386.10; df: 4; p=0.00

Table 2: Marital Status * Sex

Marital status	Sex				Total	
	Male		Female		No.	%
	No.	%	No.	%		
Divorced	0	0.00	2	0.19	2	0.11
Married	48	6.75	67	6.37	115	6.53
Married	567	79.75	923	87.82	1490	84.56
Unmarried	14	1.97	9	0.86	23	1.31
Widow/Widower	82	11.53	50	4.76	132	7.49
Total	711	100.00	1051	100.00	1762	100.00

X^2: 37.72; df:4; p=0.00

The most common type of cancer in females was Carcinoma breast which accounted for 42.06% of the total cases in female population in study followed by Carcinoma cervix that accounted to 18.84% of the total cases. However, in males the most common type of cancer was carcinoma lung that

constituted of 11.25% of the total cases followed by Ca larynx (9.42%) and then carcinomas of the buccal cavity including lip, soft palate, hard palate, floor of the mouth and gingiva that comprised of 8.58% of the total cases in male patients. The other common carcinomas were Ca tongue (7.03%), Ca oesophagus (5.91%), prostate (5.49%) and Ca Urinary bladder (4.50%). (Table 3).

On evaluating the treatment strategy, maximum number of patients received Chemotherapy that included 864 patients amounting to 49.4% of the patients. This was followed by combined chemotherapy and radiotherapy (25.09%), radiotherapy alone (21.5%), surgery and radiotherapy (1.99%), all modalities including surgery, chemotherapy and radiotherapy (1.25%). (Table 4, 5).

The patient outcome score was calculated, which is a 4-point grading of pain according to the patient i.e. 0- no pain,1- mild pain,2- moderate pain, 3 severe pain were taken in account according to the patient's complaints in the history. On recording the results, 709 patients were found to have complaint of mild pain, 644 patients complained of moderate pain and 279 patients complained of severe pain. Only 130 patients complained of no pain. The above number of patients amounted to 40.2%, 36.55%, 15.83% and 7.38% of the total patients respectively.

The analgesic treatment received by the patients was recorded. It constituted the analgesia received by the patient, which is rated on a four-point scale as follows: 0- no analgesia, 1- Nonopioid analgesic, 2- ''weak'' opioid, 3- ''strong'' opioid. It was noted that maximum number of patients received a weak opioid for pain relief i.e. 841 patients (47.7%). This was followed by 659 patients who received no analgesia (37.4%) and 247 patients who received non-opioid analgesia (14.02%). Only 0.85% patients received strong opioids.

As a performance marker of palliative care, pain management index [7, 8] was calculated which was obtained by subtracting the treatment score from the patient outcome score. The pain management index in negative corresponded to inadequate pain management while a positive score was taken as conservative or adequate pain management. In our study, the maximum number of patients had a pain management index score of -1 (897 patients out of 1762; 50.9%) showing inadequate pain management. This was followed by a pain management index score of zero that was recorded in 742 patients amounting to 42.11% of the total patients. There were 79 patients with PMI of -2 (4.48%), 38 (2.16%) and 6 patients (0.34%) with PMI of +1 and +2 respectively. (Table 6)

Table 3: Type of Cancer * Sex

Type of cancer	Sex				Total	
	Male		Female		No.	%
	No.	%	No.	%		
Adenocarcinoma	1	0.14	5	0.48	6	0.34
Alveolar Region	1	0.14	3	0.29	4	0.23
Anal Canal	8	1.13	9	0.86	17	0.96
Anorectal	12	1.69	5	0.48	17	0.96
Aryepiglottic folds	1	0.14	1	0.10	2	0.11
Arytenoids	1	0.14	0	0.00	1	0.06
Astrocytoma	2	0.28	1	0.10	3	0.17
B-cell lymphoma	2	0.28	1	0.10	3	0.17
Base of Tongue	20	2.81	5	0.48	25	1.42
Basal cell carcinoma	5	0.70	1	0.10	6	0.34
Bony mets from primary unknown	5	0.70	2	0.19	7	0.40
Intracranial Space occupying lesion (ICSOL)	4	0.56	2	0.19	6	0.34
Breast	4	0.56	442	42.06	446	25.31
Buccal Cavity (lip, soft and hard palate, floor of mouth, gingiva)	61	8.58	14	1.33	75	4.26
Cervix	0	0.00	198	18.84	198	11.24
Lung	80	11.25	17	1.62	97	5.51
Submandibular gland	5	0.70	2	0.19	7	0.40
Shin	1	0.14	0	0.00	1	0.06
Caecum	1	0.14	1	0.10	2	0.11
Cervical LAP mets	27	3.80	1	0.10	28	1.59
Cheek	2	0.28	0	0.00	2	0.11
Chest mets	2	0.28	3	0.29	5	0.28
Clitoris	0	0.00	3	0.29	3	0.17
CLL	3	0.42	3	0.29	6	0.34
CML	10	1.41	3	0.29	13	0.74
Colon/Colorectal	11	1.55	6	0.57	17	0.96
Cricoarytenoid	1	0.14	0	0.00	1	0.06
Germ cell tumor	0	0.00	56	5.33	56	3.18
Endometrium	4	0.56	34	3.24	38	2.16
Epiglottis	5	0.70	2	0.19	7	0.40
Bone	1	0.14	1	0.10	2	0.11
Fibrous histiocytoma	0	0.00	1	0.10	1	0.06
Gall Bladder	8	1.13	16	1.52	24	1.36

Giant cell tumor	3	0.42	0	0.00	3	0.17
GIST	3	0.42	0	0.00	3	0.17
Glioblastoma Multiforme	5	0.70	5	0.48	10	0.57
Hepatocellular	8	1.13	5	0.48	13	0.74
Hip	1	0.14	0	0.00	1	0.06
Hodgkin's lymphoma	7	0.98	10	0.95	17	0.96
H. Mole	0	0.00	2	0.19	2	0.11
Ileum	0	0.00	2	0.19	2	0.11
Larynx	67	9.42	7	0.67	74	4.20
Liposarcoma	6	0.84	5	0.48	11	0.62
Non-hodgkin's lymphoma	24	3.38	23	2.19	47	2.67
Mass abdomen	3	0.42	3	0.29	6	0.34
Round cell tumor	2	0.28	1	0.10	3	0.17
Malignant ulcer	1	0.14	1	0.10	2	0.11
Mandible	10	1.41	0	0.00	10	0.57
Mastoid	1	0.14	0	0.00	1	0.06
Maxilla	2	0.28	1	0.10	3	0.17
Multiple myeloma	12	1.69	12	1.14	24	1.36
Myeloid Spindle cell tumor	1	0.14	0	0.00	1	0.06
Nasopharynx	2	0.28	2	0.19	4	0.23
Oesophagus	42	5.91	38	3.62	80	4.54
Oropharynx	7	0.98	3	0.29	10	0.57
Pancreas	1	0.14	7	0.67	8	0.45
Parotid	8	1.13	13	1.24	21	1.19
Penis	6	0.84	2	0.19	8	0.45
Perianal	1	0.14	0	0.00	1	0.06
Pituitary	0	0.00	1	0.10	1	0.06
PNET	0	0.00	1	0.10	1	0.06
Posterior cricoid region	1	0.14	4	0.38	5	0.28
Posterior pharyngeal wall	1	0.14	0	0.00	1	0.06
Prostate	39	5.49	0	0.00	39	2.21
Pyriform fossa	21	2.95	4	0.38	25	1.42
Renal cell carcinoma	5	0.70	6	0.57	11	0.62
Squamous cell carcinoma	13	1.83	9	0.86	22	1.25
Testes	8	1.13	0	0.00	8	0.45
Stomach	4	0.56	2	0.19	6	0.34
T-cell lymphoma	1	0.14	0	0.00	1	0.06
Thyroid	2	0.28	3	0.29	5	0.28
Tongue	50	7.03	15	1.43	65	3.69
Tonsil	17	2.39	4	0.38	21	1.19
Ureter	0	0.00	1	0.10	1	0.06
Urinary Bladder	32	4.50	10	0.95	42	2.38
Vaginal/Vulvovaginal	0	0.00	10	0.95	10	0.57
Vocal Cords	6	0.84	1	0.10	7	0.40
Total	711	100.00	1051	100.00	1762	100.00

X^2: 1018.64; df: 77; p=0.00

Table 4: Cancer related treatment * Sex

Cancer related treatment	Sex				Total	
	Male		Female		No.	%
	No.	%	No.	%		
All	0	0.00	22	2.09	22	1.25
Chemo & Surgery	2	0.28	17	1.62	19	1.08
Chemotherapy	370	52.04	494	47.00	864	49.04
Radiotherapy	163	22.93	217	20.65	380	21.57
Radiotherapy & Chemotherapy	165	23.21	277	26.36	442	25.09
Surgery & radiotherapy	11	1.55	24	2.28	35	1.99
Total	711	100.00	1051	100.00	1762	100.00

X^2: 27.95; df:5; p=0.00

Table 5: Palliative treatment and pain management * Sex

Palliative treatment and pain management	Sex				Total	
	Male		Female		No.	%
	No.	%	No.	%		
	697	98.03	1041	99.05	1738	98.64
Radiotherapy	13	1.83	9	0.86	22	1.25
Radiotherapy to brain	1	0.14	0	0.00	1	0.06
Radiotherapy to spine	0	0.00	1	0.10	1	0.06
Total	711	100.00	1051	100.00	1762	100.00

X^2: 6.077; df: 4; p=0.193

Table 6: Palliative outcome score * Sex

Palliative outcome score	Sex				Total	
	Male		Female		No.	%
	No.	%	No.	%		
0	58	8.16	72	6.85	130	7.38
1.0	284	39.94	425	40.44	709	40.24
2.0	255	35.86	389	37.01	644	36.55
3.0	114	16.03	165	15.70	279	15.83
Total	711	100.00	1051	100.00	1762	100.00

X^2: 1.190; df:3; p=0.755

Treatment score * Sex

Treatment score	Sex				Total	
	Male		Female		No.	%
	No.	%	No.	%		
0	280	39.38	379	36.06	659	37.40
1.0	89	12.52	158	15.03	247	14.02
2.0	335	47.12	506	48.14	841	47.73
3.0	7	0.98	8	0.76	15	0.85
Total	711	100.00	1051	100.00	1762	100.00

X^2: 3.507; df: 3; p=0.320

PMI Score * Sex

PMI Score	Sex				Total	
	Male		Female		No.	%
	No.	%	No.	%		
-2.0	30	4.22	49	4.66	79	4.48
-1.0	373	52.46	524	49.86	897	50.91
.0	289	40.65	453	43.10	742	42.11
1.0	17	2.39	21	2.00	38	2.16
2.0	2	0.28	4	0.38	6	0.34
Total	711	100.00	1051	100.00	1762	100.00

X^2: 1.784; df:4; p=0.755

Discussion

Cancer remains the most dreaded diagnosis for any patient and brings immense discomfort and a feeling of despair to the family. Out of all the symptoms, pain is the most feared symptom and forms the basic foundation of the palliative treatment [9, 10] (Valdimarsdotti 2002 and winslow et al 2005 article A). As per the American Cancer society, 50% -70% of the patients experience pain (ACS 2002) and inadequate pain relief adversely affects the outcome as well as hampers the overall well being of the patients. 11 For this, the patient needs optimal analgesia along with other palliative measures such as psychological and emotional support to improve the quality of life. Palliative care will also lead to relief of end of life symptoms not only in cancer but the non-malignant terminal illnesses as well. Also, this will stop the routine and unnecessary investigations that may not contribute to the process of patient care [4] which will reduce the financial burden on the family of the patient and also the economic burden on the country. In India, 1 million new cancer patients are diagnosed every year and 80% of them are in stage IV. Thus, palliative care is the field that needs to be addressed.

In our study, the occupation of all the patients were tabulated and it was found that 1136 patients out of 1762 were unemployed (64.4%), 301 were unskilled (17.0%) and 1.42 were semiprofessional. These statistics reflect upon the socioeconomic status of the patient. As most of the patients were unemployed it can be assumed that the awareness and access to early diagnosis and treatment could have been limited. This also reflects upon the poor future continuation and compliance of the treatment which calls for a dedicated palliative care setup to counsel regarding the treatment, prognosis and improving the quality of life of the patient and the family. Palliative care can be provided as an institutional set up or as a home care facility. Many studies have found home care to be better than the institutional care [12]. Such a facility has been thriving in the state of Kerala to develop a community-based home care under the local self-government set up [13, 14] This brings down the hospital visit expenses and provides a more secure environment of home for better quality of life [15].

In our study, the retrospective analysis of terminal cancer patients was done in the city of Amritsar as it receives the majority of downpour of patients from the adjacent border areas. All the patients were in their terminal stages of the respective cancer (stage III or IV) and received radiotherapy as a treatment or palliative care. The pain management regime of the patient was noted and analyzed as the palliative outcome score. Adequate pain relief improves the productivity of a patient and helps in early mobilization and rehabilitation. Thus, pain management index can safely be taken as a marker for the palliative outcome of the patients.

On a 4-point analgesic index or palliative outcome score, it was found that more than 80% patients complained of mild to severe pain and there were only 7.38 % patients who complained of no pain. These findings are also supported by the American Cancer society statistics report published in 2002 [11].

Out of all the above patients, 37.4% received no analgesia and 47.7% received a weak opioid. There were only 14.02% patients who received non-opioid analgesia and 0.85% received higher opioids. This points towards the under treatment of pain. This can be attributed to the fact that there is no palliative care setup in Amritsar to address the issue. On further calculating the pain management index which was obtained after subtracting the palliative outcome score from the treatment score it was found that most of the patients had a score of 0 or -1 which shows inadequate pain management. Multiple surveys have been conducted over the years by various agencies including the world health organization to identify the causes of under treatment of pain [16, 17, 18]. It has been identified that lack of knowledge of opioid analgesia, overestimation of their ability to cause dependence and inability of the health professionals to calculate the equipotent doses of various opioids lead to gross under treatment of pain [19, 20, 21]. Another cause could be the popular approach of many physicians to provide 'on demand analgesia' rather than round the clock pain relief [22]. However, in the city of Amritsar there could be numerous other reasons that can be attributed to the under treatment of pain which are the strict drug protection act that makes the procurement of strong opioids very difficult. Although some opioids are available in the government pharmacies, stronger opioids like fentanyl and their newer delivery formulations are sparsely available. This is due to the increasing drug abuse problem that limits the availability of dependence causing drugs. Some of these are even banned under the national drug protection act.

Another reason for this under treatment could be the lack of exploration of alternate pain relieving treatments such as nerve ablation techniques and nerve blocks. These techniques are highly under utilised which can be due to lack of awareness, lack of inter departmental communication. As seen in our study not even a single patient received any nerve block or ablation despite a fully functioning pain clinic. Lack of awareness among patients and lack of referral to the required facility leads to these setbacks. With an everyday increasing incidence of cancer and other chronic diseases due to increased life expectancy, a fully equipped palliative care centre is the need of the hour and the Kerala model can be taken as an inspiration to cater to the population suffering from terminal diseases to provide end of life care and improve the quality of life.

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