

## Improving Quality of Life in Cancer Patients

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**Abstract:** Pain and Palliative Care Clinic (PPC).

**Aims:** The primary object of this study was to enumerate the demographic characteristics of patients attending a newly organized PPC. The secondary purpose was to detect symptom prevalence and frequency of different cancers in these patients and the objective was to reach out to the patient and help in improving the patient's quality of life in every way possible.

**Settings and Design:** Prospective cross-sectional descriptive study.

**Materials and Methods:** A prospective cross-sectional descriptive study was done on patients referred to the PPC of a Tertiary hospital in J&K India. Comprehensive details of all patients were recorded systematically on the first visit on a proforma specially prepared for the newly established Palliative Care Clinic.

**Statistical Analysis Used:** The descriptive statistics of Palliative care data was presented in terms of frequencies and percentages (%) for categorical variables.

**Results:** The data collected at our PPC showed that out of 156 patients, 90 were males and 66 were females. Patients of all ages varying from 20 to 90 years were seen. Most patients 145 (93%) lived with their families, and 11 (7%) patients lived alone and had no financial support. The most common primary diagnosis were Carcinoma Lung 36 (23.07%), Carcinoma Esophagus 34 (21.79%), Carcinoma Breast 15 (9.61%), Unknown Primaries with Secondaries elsewhere 12 (7.69%), Genitourinary tract malignancies 08 (5.12%), Colorectal carcinoma 7 (4.48%), Gall Bladder carcinoma 05 (3.20%), Pancreas carcinoma 04 (2.56%) and all others like Soft tissue Sarcoma, Skin cancers, Schwannomas, Multiple Myeloma, Nasopharyngeal Carcinoma, Carcinoma Buccal cavity, Carcinoma Orbit, Astrocytomas/Paragangliomas were 18 (11.53%). Frequency of seven most common symptoms was pain (100%), insomnia (64.1%), loss of appetite (34.6%), nausea (32.7%), vomiting (32.1%), constipation (31.4%) and sore mouth (28.8%).

**Conclusions:** Population-based studies determine the actual magnitude of sufferers and suffering and show that palliative care services should be included as an essential component in a tertiary care hospital. The objective should be to reach out to the patient and help in improving the patient's quality of life in every way possible.

### I. Introduction

Demographic and epidemiological transitions and changes in lifestyle are leading to emergence of cancer and other chronic diseases as major public health problems in India. Cancer patients in Jammu and Kashmir reveal the prominence of tobacco, life style changes and food habit-related cancers, which are amenable to primary prevention. Cancer registries in different parts of the country reveal that majority of cancer cases present in advanced stages and make treatment options prolonged and expensive. Therefore, the need for prevention, early detection and provision of pain and palliative care is mandatory in the holistic management of cancer.

### II. WHO Definition of Palliative Care

Palliative care 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. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care is in preliminary stages in J&K India. Whereas the number of palliative care services along with clinical and epidemiological programs is increasing in western industrialized countries, in the developing world it remains at a dramatically low level.

The primary object of this study was to evaluate the demographic data of patients attending the newly organized pain and palliative care clinic (PPC) service in a tertiary hospital in North India. The second purpose was to detect the frequency of symptoms and prevalence of different cancers in these patients. This may be regarded as the first step to the continuing audit program in this newly organized specialty.

### III. Materials and Methods

The study presents a total of 156 patients who were referred to the PPC of a tertiary hospital in North Indian state of J&K by Oncologists. This was a prospective cross-sectional descriptive study. Relevant data was collected on a record sheet specially prepared for the clinic. All efforts were made to get maximum information during the first visit of the patient. The proforma included the patient's history, diagnoses made based on biopsy findings, metastasis, prevalence symptoms, medications complementary medications, intensity of pain [Visual Analogue Scale (VAS) scores 1-10], type, radiation and character of pain, and response to treatment given in our clinic. Symptoms were recorded at the first visit and then throughout the palliative care period. The main objective was to initiate totality of care as early as possible. Patients with diagnosis other than cancer were excluded. Patients visited the clinic regularly, based on the appointments made at the last visit or earlier if the patient had any complication or no relief from pain. A large number of patients came from far off rural areas and depended on family support for coming to the clinic. The descriptive statistics of palliative care data was presented in terms of frequencies and percentages(%) for categorical variables. The survey did not involve any therapeutic interventions on the patients and did not lead to documentation of data other than that recommended for routine assessment and quality assurance.

### IV. Results

Out of 156 patients, 90 (57.7%) were males and 66 (42.3%) were females. The age of these patients ranged from 20 to 90 years. 70% of patients having cancer were in the age group of 30-60years. Most patients lived with their families 145 (93%) and had family support, whereas 11 (7%) patients lived alone and had no financial support. The income of most patients was low, with 50 (32.05%) patients below poverty line, 43 (27.56%) in low-income group and 56(35.89%) in middle-income group; only 7 (4.48%) patients were from a high-income group which implies that financial support was a major issue.

**Table:1:Age, Sex, and demographic characteristics of Patients:**

Characteristics	Frequency	Percentage
<b>Age(Years)</b>		
0-30	14	8.97
30-60	109	69.87
60-90	33	21.15
<b>Sex:</b>		
Male	90	57.7
Female	66	42.3
<b>Category:</b>		
Rural	105	67.30
Urban	51	32.69
BPL	50	32.05
LIG	43	27.56
MIG	56	35.89
HIG	07	4.48

**BPL:** Below Poverty Line.

**LIG:** Low Income Group.

**MIG:** Middle Income Group.

**HIG:** High Income Group.

In our study, the most common primary diagnosis were Carcinoma Lung (23.07%), carcinoma Oesophagus (21.79%), Carcinoma Stomach/GE Junction (10.89%), Carcinoma Breast (9.61%),Unknown Primary with secondaries (7.69%), Colorectal Carcinoma (4.48%), Carcinoma Gall Bladder (3.20%),Carcinoma

Pancreas(2.56%),Genitourinary Tract Carcinoma (5.12%) and all others including Schwannoma, Multiple Myeloma, Soft tissue sarcoma, Paraganglioma, Triple Malignancy, Carcinoma Nasopharynx, Carcinoma Buccal cavity, Carcinoma Tongue, Carcinoma Skin, Carcinoma Orbit, and Astrocytoma were 11.53%.

**Table 2: Cancer Type**

Primary site	Total(N=156)	Percentage
Lung	36	23.07
Esophagus	34	21.79
Stomach	17	10.89
Breast	15	9.61
Unknown Primary	12	7.69
Pancreas	04	2.56
Colorectal Carcinoma	07	4.48
Gall Bladder	05	3.20
Genitourinary Tract	08	5.12
Others	18	11.53

The average number of symptoms at the first consultation was 5 per patient. Ten different types of symptoms related to the illness were recorded during the first consultation. In the present study, frequency of various symptoms was recorded as pain (80.76%), Insomnia (70.51%), loss of appetite (43.59%), nausea (18.59%), vomiting (8.33%), constipation (33.33%), sore mouth (4.49%), dysphasia (3.20%), cough (2.56%), and urinary symptoms (5.78%).

**Table 3: Symptoms of the Patients:**

Symptoms	Frequency	Percentage
Pain	126	80.76
Insomnia	110	70.51
Loss of appetite	68	43.59
Nausea	29	18.59
Vomiting	13	8.33
Constipation	52	33.33
Sore Mouth	7	4.49
Dysphasia	5	3.20
Cough	4	2.56
Urinary Symptom	9	5.78

Pain was the main symptom. The majority of patients had pain of moderate intensity(67.27%). Severe pain was present in 18.18% patients and mild pain was there in only 14.54% patients. Twenty percent patients had pain duration of more than 3 months. 30% patients had pain for the last 2-4 months, 40% had pain for 1-2 months, 8% had pain for less than 1 month and 2% had pain lasting more than 6 months. Majority of patients (67.3%) had increased pain during the night and 25.6% had pain all the time. Radiation of pain was observed in 40% patients.

As part of treatment, 33.3% patients had undergone surgery, 89.7% had received radiotherapy and 75.8% had received chemotherapy before visiting the PPC. 65.5% patients were on palliative therapy by the time they were referred to PPC.

A total of 19% patients had taken some complementary therapy, other than allopathy. Maximum number (12.8%) took homeopathy, 2.6% took ayurveda and only 3.6% resorted to naturopathy. Due to lack of aggressive palliative care, patients sought alternative therapies to overcome their problems.

## **V. Discussion**

This study provides an understanding of the type of patients, their diagnosis and the symptom manifestation across a range of cancer patients who become identified as incurable by their treating physicians. The increasing number of patients attending the pain and palliative clinics shows that the specialty is evolving and other professionals are recognizing the need for the specialized Palliative care service. Though the absolute number may be less, considering the different barriers to referral of the patients to the palliative care clinic by other disciplines, patient barriers of travelling to another clinic and lack of knowledge of the services offered, family barriers in assuming the clinic to be an end of life support clinic indicate a long way has to be traversed before palliative care can be offered to most of the patients in need. Similar studies done in other developing countries showed similar problems. The symptoms of the persons in the terminal phase of illness have been documented in a number of studies conducted in different countries. These studies show that the terminal phase of illness is associated with increased physical as well as significant psychological disturbances.

The male to female ratio in our study was comparable to other studies, which probably implies that the need for comfort care is equally appreciated for both sexes by their family members. The wide age range shows that no age is exempt from this dreadful, life-threatening disease. While it is not surprising that these patients present in the PPC with myriad of symptoms, it is of concern that these patients were already being treated by physicians, often specialists, and were still suffering from severe symptoms. This could be explained by the fact that a patient who reports to have pain as the main symptom may have needs that actually go far beyond a simple physical complaint of pain. However, the complexity of patients' complaints is often underestimated by physicians and may account for a lack of referral. Altered symptom expression may be caused by factors such as impaired cognition or emotional existential or family distress and may not be recognized in busy Oncological clinics. Moreover, it was observed, the primary care provider often addresses the therapeutic modalities like surgery, chemotherapy, and radiotherapy very aggressively till the very end of disease without really attending to the comfort issues of the patients such as pain, which often accounts for the delay in referrals. Pavne Sa (1992) studied the quality of life in cancer patients receiving palliative chemotherapy. In this study it was revealed that the primary treatment for cancer has been associated with psychosocial distress, less research has focused on patients with advanced disease. Traditionally, the outcomes of treatment have been assessed using biomedical criteria, including tumour regression, progression and survival. It is argued that these data are inadequate to understand the impact of cancer upon the patient. Instead, quality of life considerations are crucial when treatments are aversive, especially when the aims are palliative rather than curative. Fifty-three patients with advanced breast cancer or ovarian cancer were studied prospectively for 6 months to assess whether the site and method of chemotherapy administration influenced their quality of life. Patients received palliative chemotherapy either at home or in hospital. Quality of life was operationalized as measurement of anxiety, depression, self-esteem, health locus of control, physical performance and symptoms. In addition, semi-structured interviews explored social roles, relationships, and perceptions of treatment. Hospital administered chemotherapy was perceived to be most distressing. Regression analysis indicated that anxiety and depression accounted for most of the variance in quality of life. Patients who died during the study 13 (24%) experienced considerable psychological and physical morbidity. Women over 60 years, experienced less psychological and physical distress. Quality of life broadens the criteria by which cancer treatments are evaluated, to include the experience of the patient. In Daren K. Heyland et.al (2006) studied perception of seriously ill patients and their family members. In this study it was carried out that 569 eligible patients and 176 family members, 440 patients (77%) and 160 relations (91%) agreed to participate. The elements rated as "extremely important" most frequently by the patients were "To have trust and confidence in the doctors looking after you" (55.8% of respondents), "Not to be kept alive on life support when there is little hope for a meaningful recovery" (55.7%), "That information about your disease be communicated to you by

your doctor in an honest manner” (44.1%) and “To complete things and prepare for life’s end — life review, resolving conflicts, saying goodbye”(43.9%). Significant differences in ratings of importance between patient groups and between patients and their family members were found for many elements of care. In William Breitbart (2000) studied depression, hopelessness and desire for hastened death in terminally ill patients with cancer free. They revealed that 569 eligible patients and 176 family members, 440 patients (77%) and 160 relations (91%) agreed to participate. The elements rated as “extremely important” most frequently by the patients were “To have trust and confidence in the doctors looking after you” (55.8% of respondents), “Not to be kept alive on life support when there is little hope for a meaningful recovery” (55.7%), “That information about your disease be communicated to you by your doctor in an honest manner” (44.1%) and “To complete things and prepare for life’s end — life review, resolving conflicts, saying goodbye”(43.9%). Significant differences in ratings of importance between patient groups and between patients and their family members were found for many elements of care.

Though the concept of "Terminal Cancer Syndromes" is independent of age, sex, and histological cancer type as well as metastatic pattern, yet detailed evaluation and management of symptoms among patients dying from different incurable diseases will be helpful to the clinicians and contribute to improved patients' quality of life. In our study, pain was the most common presenting complaint which was found to be moderate to severe in majority of our patients, and unbearable in a few in spite of some basic analgesic care that the patient was already taking. This clearly shows the lack of concern to this most distressing symptom. The second most common symptom in our group of patients was insomnia, which is similar to the findings of others who find it as a major concern after pain. Insomnia was found to be the consequence of pain in most of our patients. The other two important symptoms observed in most studies were that of fatigue and loss of appetite. Two multicenter analyses done abroad, one by Kutner *et al.* shown lack of energy as the commonest symptom, and another one by Vainio *et al.* found tiredness as a prominent symptom. These symptoms significantly affected the patient's daily routine and "quality of life." Although professional psychological assessment could not be done in our patients, most patients did have obvious signs of depression. This appeared to be both due to physical symptoms and also awareness of the prognosis of the disease. A psychological support system in this respect would provide them better care. Most of the patients had complaints of nausea, vomiting, anorexia, heartburn, urinary symptoms, oral ulcers, sore mouth and constipation. In accordance with the findings in other studies, we observed that pain, nausea, vomiting and anorexia were more easily treated than fatigue and depression. Many patients with advanced cancer undergo a wasting syndrome characterized by anorexia, loss of weight, asthenia, and a poor prognosis, referred to as the cancer anorexia/cachexia syndrome. In defining these terms further, anorexia describes loss of appetite and/or an aversion to food. The term “cachexia” refers to a loss of body mass, including lean body mass and fat, in the setting of a disease state, in this case cancer. In a study that assessed symptoms in cancer patients being entered into a palliative care service, anorexia/cachexia and asthenia were more common than pain or dyspnea, but typically such symptoms cluster within the top five as the most troubling and bothersome for cancer patients approaching the end of life. Patients who exhibit such signs and symptoms generally have a short survival time, respond poorly to chemotherapy agents, and suffer increased toxicity from these agents. In addition, cancer anorexia/cachexia often is associated with weakness, fatigue, and a poor quality of life. This symptom of anorexia not only affects the patient but also frequently has a negative impact on family members, in part because the patient is no longer able to participate fully in eating as a social activity. The lack of concern of the primary treating team toward the symptom complex and the stress laid only on the definitive treatment led the patients to seek various modes of alternative therapy such as homeopathy, ayurveda and naturopathy before presenting to the PPC. In E.A Thomas *et al.* (2003) studied the homeopathic approach to the treatment of symptoms of oestrogen withdrawal in breast cancer patients. This paper reports on an investigation of the homeopathic approach to the management of symptoms of oestrogen withdrawal in women with breast cancer. Forty-five patients entered the study. The most common presenting symptoms were hot flushes (HF) ( $n = 38$ ), mood disturbance ( $n = 23$ ), joint pain ( $n = 12$ ), and fatigue ( $n = 16$ ). Other symptoms included sleeplessness, reduced libido, weight gain, cystitis, vaginal dryness and skin eruptions. The active intervention was an individualised homeopathic medicine. Forty women (89%) completed the study. Significant improvements in mean symptom scores were seen over the study period and for the primary end-point ‘the effect on daily living’ scores. Symptoms other than HF such as fatigue and mood disturbance appear to be helped. Significant improvements in anxiety, depression and quality of life were demonstrated over the study period. The homeopathic approach appears to be clinically useful in the management of oestrogen withdrawal symptoms in women with breast cancer whether on or off Tamoxifen and improves mood disturbance. A placebo-controlled trial would be the next stage in this line of inquiry.

## VI. Effects of Cancer Treatment on Nutrition

### Surgery and Nutrition

- Surgery increases the body's need for nutrients and energy.
- Surgery to the head, neck, esophagus, stomach, or intestines may affect nutrition.
- Nutrition therapy can help relieve nutrition problems caused by surgery. Chemotherapy and Nutrition
- Chemotherapy affects cells all through the body.
- Chemotherapy may affect nutrition.
- Nutrition therapy can help relieve nutrition problems caused by chemotherapy.

### • Radiation Therapy and Nutrition

- Radiation therapy can affect cancer cells and healthy cells in the treatment area.
- Radiation therapy may affect nutrition.
- Nutrition therapy can help relieve the nutrition problems caused by radiation therapy.

### • Biologic Therapy and Nutrition

- Biologic therapy may affect nutrition.
- Nutrition therapy can help relieve nutrition problems caused by biologic therapy.

### Suggestions to overcome eating related problems during treatment

Side effects of treatment	What to do
Mouth sores	<ul style="list-style-type: none"> <li>➤ Frequent small meals and snacks, soft in texture</li> <li>➤ Lukewarm or cold foods rather than warm</li> <li>➤ Soft foods like custard, milkshakes, lassi</li> <li>➤ Avoid foods that irritate the mouth-spicy or salty food , citrus fruit juices-lemon, orange</li> <li>➤ Drink through a straw</li> <li>➤ Maintain oral hygiene</li> <li>➤ Avoid alcohol,caffeine and tobacco</li> </ul>
Dry mouth	<ul style="list-style-type: none"> <li>➤ Lots of fluids to loosen mucus</li> <li>➤ Fluids high in citric acid content such as orange juice to stimulate saliva production</li> <li>➤ Take small bites and chew food well</li> <li>➤ Keep mouth clean</li> <li>➤ Avoid foods that stick to the roof of the mouth</li> </ul>
Gum and dental problems	<ul style="list-style-type: none"> <li>➤ Soft brush for brushing teeth</li> <li>➤ Avoid sugary and sticky foods</li> </ul>
Difficulty in swallowing	<ul style="list-style-type: none"> <li>➤ Liquids or semi solid foods at frequent intervals</li> <li>➤ Milkshakes, custard, pudding, strained chicken/ mutton soup.</li> <li>➤ Mashed potatoes with butter cream</li> <li>➤ Soft scrambled egg</li> <li>➤ Soft well cooked, bland food like khichdi, curd rice</li> </ul>
Changed sense of taste	<ul style="list-style-type: none"> <li>➤ Foods that look appetizing</li> <li>➤ Flavouring foods with new tastes or spices</li> <li>➤ Foods cold or at room temperature. This can decrease the food's taste and smells, making them easier to tolerate</li> <li>➤ Liquids with meals to rinse away any unpleasant taste</li> <li>➤ Clean mouth to relieve bad tastes</li> </ul>
Nausea and vomiting	<ul style="list-style-type: none"> <li>➤ Dry foods like toast or biscuit on waking up and every few hours during the day</li> <li>➤ 6-8 meals instead of 3 big meals</li> <li>➤ Avoid foods that are greasy, too sweet, fried or spicy or with strong flavour</li> <li>➤ Eating slowly and chewing thoroughly</li> </ul>
Poor appetite	<ul style="list-style-type: none"> <li>➤ Eating small meals every 1-2 hours</li> <li>➤ Liquids or semi solids with nutrition supplement if there's a dislike for solids.</li> <li>➤ Avoid filling the stomach with a large amount of liquid before eating; drink after meals</li> <li>➤ Having food in pleasant atmosphere</li> </ul>
Diarrhoea	<ul style="list-style-type: none"> <li>➤ Plenty of fluids to replenish electrolyte loss</li> <li>➤ Avoid high fibre food .</li> </ul>

	<ul style="list-style-type: none"> <li>➤ Avoid greasy , fried, spicy or sweet food</li> <li>➤ Small frequent meals during the day</li> </ul>
Weight loss	<ul style="list-style-type: none"> <li>➤ Calorie and protein dense supplements in addition regular diet.</li> </ul>
Unwanted weight gain	<ul style="list-style-type: none"> <li>➤ Take fruits and vegetables in good amounts</li> <li>➤ Lean meat and low fat diary products</li> <li>➤ Cut down on added butter, sweets</li> <li>➤ Avoid sweets and high fat food</li> <li>➤ Activities that will help relieve stress</li> <li>➤ Daily walks as tolerated and with doctor's approval</li> </ul>

### **VII. Conclusion**

It may be concluded that majority of patients referred to our Pain and Palliative Care Clinic were suffering from Ca. Lung and Ca Esophagus and followed by other malignancies. Among majority of these patients pain was the main symptom of distress and discomfort and other symptoms like insomnia, loss of appetite, fatigue etc were directly or indirectly related with pain. It was observed that when proper management of pain was done. Other symptoms improved dramatically. It was also observed that inclusion of palliative care in early stage of cancer improved the quality and quantity of patients life. It was also concluded that the Palliative care clinic should have a multidisciplinary approach with aspects of psychological, social and financial support given equal emphasis. Last but not the least, awareness and sensitization of the primary health care providers in recognizing and treating pain and other symptoms occurring due to malignancy or due to treatment given for the disease and the need for early referral to Palliative care clinic and not as a terminal resort is mandatory.

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