Palliative Care Tailored Towards the Needs of the Poor in India

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Abstract Traditional approaches to palliative care may not meet the unique needs of poor cancer patients in developing countries. Cancer patients treated in India are often unable to make repeat visits to the hospital, pay for drugs, or understand and follow complex treatments. Many are from rural areas and may lack basic financial or social support. Our palliative care clinic has taken a series of innovative first steps towards meeting these unique needs, from providing treatment without complete diagnosis, accelerating through the World Health Organization (WHO) analgesic schedule, systematically simplifying prescriptions, and providing treatment free of charge. This paper describes these first steps, presents an initial evaluation of their impacts, and articulates a number of opportunities for additional improvements.

Keywords Palliative care · Cancer · Diagnosis · Prescriptions

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Introduction

Moderate to severe pain is the most common symptom patients present with at the palliative care clinic (PCC). Unrelieved pain causes unnecessary suffering and can be psychologically devastating for the cancer patient, often resulting in physical and mental exhaustion, loss of hope, and an undermining of the value of life [1–3]. With the plethora of medications and techniques available, however, the problem of pain relief has been largely addressed.

In addition, however, the literature [4–9] and our experience suggest that patients look to the palliative caretaker to address other critical issues, such as psychological distress, financial support, family and social concerns. This suggests that palliative care should take a comprehensive approach towards a patient with cancer and not focus only on the relief of physical symptoms. Moreover, while the number of symptoms and intensity of pain has been used as an outcome measure for palliative care [10] this further suggests that patient satisfaction with the overall approach to palliative care (not just pain) can serve as an important outcome parameter.

Many of these needs are acute in our PCC. Launched in 2009, our PCC serves a large number of poor and illiterate patients who often live very far from the city—up to 400 km sometimes. In this study, we describe a number of novel steps that we have taken to respond to our patients diverse and serious needs. We have also sought to better understand how these steps and our PCC system as a whole meets patient needs. To this end, we audited and analyzed the responses of the initial 156 patients attending our PCC, in terms of pain relief and overall patient satisfaction along several dimensions.

Methods

The use of a PCC has not been mainstreamed into cancer treatment in most hospitals. As a consequence, the radiation oncology, surgical oncology, and medical oncology departments at our hospital, as in many other hospitals, usually refer patients to the PCC at the last stages of life, when they are unable to manage the pain and related symptoms. Typical pain management centers, including PCCs, begin treatment regimens only after lab tests and diagnoses are finalized. However, this approach does not meet the unique needs of PCC patients, who have typically suffered for a long time, and whose objectives are to manage end of life pain rather than to improve long-term quality of life.

This approach poses significant, sometimes insurmountable, barriers for many patients at our hospital. Most patients are uneducated and from low socioeconomic backgrounds. They have difficulty following complex prescriptions and are often unable to afford routine analgesics for more than a week. Many are also rural and come to the hospital from neighboring states. In Delhi, they stay in a very basic shelter provided by the hospital. Separation from family reduces family support and makes repeated visits difficult. Where patients are primary earners, visits to the hospital mean further reductions in income. These stresses suggest that an alternative approach is warranted.

With this in mind, the PCC at our hospital has tried to improve treatment with four measures:

1. Rapid initiation of pain treatment;
2. More aggressive advancement through World Health Organization (WHO) regimen;
3. Simplified prescriptions with active patient participation; and
4. On site and free access to medications.

First, we start the pain therapy as soon as patients arrive and based on the existing patient data. We do not require any additional referrals or lab tests.

Second, we base our choice of drug on the severity of pain and not on the stage of disease. The treatment begins at an appropriate step of the WHO regime (Table 1), depending on the severity of pain. All patients having moderate to severe pain are given a trial of opioid analgesia. If pain relief fails

with a particular opioid, we advance the patient to the next step of treatment with a stronger opioid, rather than trying alternative opioids of the same potency. We add adjuvant analgesics whenever required, depending on the nature of the pain (Table 2).

Third, we encourage patients to take an active role in their pain management. We explain the treatment in detail to the patients in their own language to their family. Prescriptions are written legibly and on the WHO principles of ‘*by the mouth*’, ‘*by the clock*,’ and ‘*by the ladder*.’ Moreover, we keep the treatment as simple, prescribing the minimum number of drugs in the most acceptable form and dose interval possible. We also provide written guidance for the patient and family to reinforce the drug regimen. We encourage patients to take medication regularly for best results. Finally, given that most patients have a low socioeconomic status and are not local, the hospital provided most medicines on site and free of charge.

Satisfaction Assessment

For every patient, we recorded patient data including demographic profile, diagnosis, and status of metastasis, comorbid conditions, and concurrent medications. We also noted functional and psychological status, as well as any social or financial problems. We recorded symptoms at the start of palliative care and throughout the care period.

Each patient was assessed for all aspects of pain: its intensity, radiation, type and temporal factors. Pain was assessed using a simple visual analogue scale (VAS), as most patients came from a rural background and were unable to complete questionnaires. At referral, pain distribution was recorded using body charts, and its severity was rated as mild (VAS 0–3), moderate (VAS 4–6) and severe (VAS 7–10). Pain relief was assessed again after two weeks and thereafter every 4 weeks.

Patient satisfaction was assessed using an ad-hoc questionnaire, based on one developed by Strasser et al. [11] and modified by the palliative care team. In the questionnaire, the patients were asked to respond to the following statements using

Table 1 The WHO analgesic ladder

Step	Treatment
Step 1	Non opioid±Adjuvant
Step 2	Opioid for mild to moderate pain±Non opioid+Adjuvant
Step 3	Strong opioid+Non opioid+Adjuvant

Table 2 Adjuvant analgesics

Drugs	Indications
NSAIDs	Bone pain, Soft tissue infiltration
Corticosteroids	Raised ICP, Soft tissue infiltration, Nerve compression
Anti depressants and anticonvulsants	Nerve compression, paraneoplastic infiltrates
Bisphosphonates	Bone pain
Pregabalin/gabapentine	Neuropathic pain

NSAID non-steroidal anti-inflammatory drugs, *ICP* intracranial pressure

a scale of 1 (not satisfied) to 5 (very satisfied). Patient satisfaction scores were assessed after the 4th week.

1. The PCC team member gave me adequate time to explain my symptoms/ concerns.
2. Team members reviewed my symptoms and treatment plan with me and my family members.
3. Detailed written treatment recommendations were given properly and explained patiently.
4. I followed the recommendations as prescribed.
5. Overall I felt satisfied.

Statistical Analysis

Data analysis was performed using the software STATA version 12.0. The descriptive statistics was presented in terms of frequencies and percentages (%) for categorical variables. Paired t- test was applied to analyze the difference and level of significance between various values of VAS score at 1st visit and on follow up at 4th week after treatment. The difference was considered significant if p value was less than 0.05.

Results

The average age of 156 patients, 87 male and 69 female was 41.5 years (Table 3). Most patients 138 (88.5 %) came for

Table 3 Socio-demographic characteristics

Characteristics	Frequency	Percentage
Age (years)		
<40	48	30.77
40–49	36	23.08
50–59	42	26.92
>60	40	25.64
Sex		
Male	69	44.23
Female	87	55.77
Place of residence		
Rural	45	28.85
Urban	111	71.15
Socioeconomic status		
BPL	45	28.85
LIG	63	42.17
MIG	48	40.38
Caregiver		
Yes	128	82.05
No	28	17.95

BPL below poverty line, LIG low income group, MIG mid income group

palliative treatment and only 11.5 % were undergoing any form of curative treatment by the time they were referred to the PCC, while the most patients 128 (82 %) had social support, 18 % had no caregiver. Financially 108 patients were from lower income group with 45 below poverty line.

Proportion of mild, moderate, severe and unbearable pain changed significantly on follow up after treatment as compared to the first visit (Table 4). The number of patients having mild and moderate pain changed from 10 and 73 to 83 and 26 respectively which was statistically significant (p value <0.01). Likewise, the number of patients having severe and unbearable pain reduced from 61 and 12 to 15 and zero respectively which was also statistically significant (p value <0.01). Thirty two patients were lost to follow up because of various reasons including terminal illness in most patients.

Adjuvant treatment included gabapentin, pregabalin, muscle relaxants and some other medications like antiemetics, antacids, laxatives were required in 76.9 % of patients while tryptomer/ other antidepressants were required in more than 80 % of patients.

Discussion

Pain in a terminally ill patient is multidimensional [7–9]. Severity of pain is influenced not only by the degree of tissue damage but also by the emotional context in which it is endured [12, 13]. Pain tolerance is raised by an empathetic and supportive attitude of the care provider. If the patients are provided with an opportunity to explain their symptoms in detail and encouraged to take active role in the pain management, they feel satisfied.

Patients with advanced cancer pain often experience physical, psychological, social, and existential disorders associated with the disease or its treatment [5, 6, 13] but the needs of those patients and their families may not be completely met by standard care [11, 14, 15] This may be due to lack of a compassionate or sympathetic attitude towards these problems or due to a purely ‘clinical’ approach to the physical symptoms alone.

Table 4 Response assessment

VAS	First visit	% age	Follow up	%age	p value
(N=156)			(N=124)		
Mild (0–3)	10	6.4	83	66.9	<0.01**
Moderate (4–6)	73	46.8	26	21	<0.01**
Severe (7–10)	61	39.1	15	12.1	<0.01**
Unbearable	12	7.7	0	0	<0.01**

32 patients were lost to follow up

**Statistically Significant

The present study was planned at a newly established PCC with an aim to achieve reduction in pain scores along with improving patient satisfaction by means of simple interventions like providing analgesics as per the WHO guidelines, keeping the treatment regimen as simple as possible, devoting ample time to the patients and the accompanying family members, and providing written guidance to reinforce drug therapy.

Various studies document the symptoms of patients in the terminal phase of illness, and results show that physical symptoms of patients are associated with increased distress as well as major depression and anxiety [7, 11, 13, 16–19]. The assessment of distress should therefore be a vital aspect of clinical care in advanced and incurable diseases.

We assessed pain relief at our PCC using the VAS score. We found that 93 % of patients presented at the PCC with moderate to severe pain, although they had been on some analgesic prescribed by their primary care physicians, with 7.7 % of patients having “unbearable” pain. “Unbearable” pain was defined as a patient not having any pain free period during the entire day, and having severely disturbed sleep patterns with no sleep for more than 3 nights per week.

On the first follow up, we found that more than 92 % of patients had only mild pain (VAS<3), out of which 48.9 % of patients were completely pain free (VAS=0). This shows a significant improvement over the initial visit and demonstrates the effectiveness of the analgesic therapy. It also suggests that dosing and timing were acceptable to patients.

Further, 76.9 % of patients required adjuvants such as pregabalin, gabapentin, muscle relaxants, etc. in addition to the WHO ladder analgesics. However, only 17.4 % of patient’s required supplemental blocks. These were patients who did not respond well to the drug regimen alone.

We found that other than judicious combinations of non-steroidal anti-inflammatory drugs (NSAIDs) and opioids, a prophylactic approach towards their side effects is also important. For example, prescribing drugs like pantoprazole and domperidone to all patients anticipating gastric irritation, or laxatives for patients on morphine therapy, helped improve patient compatibility with our analgesic regimen [13].

In the analysis of patients overall satisfaction, we found that 67 % of patients scored the PCC at a 4 or 5, indicating over all satisfaction with the therapy and our approach. 12 % scored the PCC from 1 to 3, suggesting they were not overall satisfied, despite effective pain management. We could have probed patients in this latter group further to better understand the reasons for their dissatisfaction. Nevertheless, we perceived informally that many were depressed and had concerns about the financial welfare of their families into the future. They were also worried about whether they would have the family support that ongoing treatment requires.

We believe that patients can be further helped by having a multidisciplinary approach in the PCC involving professional support of psychologists and social workers. Further, they

would benefit from financial support for costs beyond medication, like lost family income, cost of visits to the hospital, and in some cases even to afford a treatment for the patients.

A major concern was the loss of follow up from 20.5 % of patients who did not return for a subsequent visit. We speculate that some of them were advised and probably took refuge at cancer care homes. Since 70 % of our patients are rural, many times coming from very remote villages, they might have found it difficult to come for the second visit. Others may not have had the family support or caregiver needed to return. Still others may not have survived to the second visit. In the future we hope to take three measures:

- Retain contact numbers of the patient and proactively reach out to them if they do not return,
- Create a 24 h hotline or contact point for patients to call and receive guidance at their homes,
- Educate medical staff at rural healthcare services about palliative care and utilize their help in patient follow up.

Conclusions

To conclude, our approach controlled patients pain well. This was the primary concern of the majority of our patients. We attribute our success to a streamlined pain management process with simple prescriptions, active participation on the part of the patient and family, and free on-site availability of drugs.

We believe that further improvement in satisfaction scores could be achieved by a multi-disciplinary approach towards the palliative care that involves psychologists, financial organizations, and social workers. We also anticipate that the loss to follow up during subsequent visits could be addressed by better communicative services with the patient and involvement of the rural health care provider. Our ultimate aim is to achieve domiciliary palliative care for all our patients.

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Ethical Standard The survey did not involve any therapeutic interventions on patient and did not lead to documentation of data other than that recommended for routine assessment and quality assurance. Therefore, approval of ethical committee was not required.

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