

POINT OF VIEW

Essential Yet Neglected Role of Primary Care Physicians in Palliation Team

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Abstract

Quality home-based care for patients with the end-stage disease is increasingly being preferred. Responding to disease associated symptoms and complications may pose an array of challenges in evolving palliative care systems, as no formal institutional mechanism exists to respond to patient and caregiver's wishes. Family and primary care physicians can play an instrumental role in such scenarios by bridging the gaps between cancer specialists and patient and caregivers expectations.

Introduction

Palliative care, especially at end-stage, focusses primarily on maintaining comfort and quality of life. Home-based palliative care is preferred for receiving the end of life care and recognized as a cost-effective option.¹ National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke (NPCDCS) has introduced need of home-based palliative care team comprising of nurse and counsellor trained in identifying symptoms, pain management, communication, psychosocial and emotional care.² This is a quintessential step towards addressing nursing needs of terminally ill patients.

Field Experience

A 55-year-old female with 20 years' history of tobacco chewing presented with a non-healing ulcer at the base of tongue for past 6 months associated with complaints of progressive speech disturbance and difficulty in swallowing and masticating food. Local examination revealed solitary midline ulcer of approximately 2cm x 2cm size on the outer surface of the floor of the mouth. Mouth opening was restricted to three fingers and tongue appeared dry with white adherent patches observed in the buccal cavity. Caregivers reported three episodes of hematemesis in the past that resolved spontaneously.

A punch biopsy from the left lateral border of tongue revealed moderate to poorly differentiated squamous cell carcinoma. Magnetic resonance image of a face to the neck from the base of the skull to clavicle showed a poorly circumscribed large mass of intraoral tongue centered along the left lateral margin measuring 5.2 cm x 3.8 cm x 6.4 cm in size. Infiltration of intrinsic tongue muscles with contralateral extension across the lingual septum with a tumour extending to right lateral tongue margin was present. Posteriorly, the tumour extended into left retromolar trigone. Anteriorly, there was destructive involvement of body of the mandible in bilateral para-sagittal planes with tumoural extension in anterior subcutaneous soft tissue across mandible. On the coronal image, the floor of the mouth and myelohyoid sling appears infiltrated. No focal osseous metastatic lesion was visible (Figures 1 and 2). Diagnosis of Squamous cell cancer oral tongue Stage IV "Loco-regionally Advanced Tongue Cancer" was made by the oncologist. Malignancy was considered inoperable and management plan defined was to initiate palliative care with an emphasis on symptoms guided preventive and therapeutic measures.

Detailed treatment history revealed visits to multiple private and public practitioners including those from an alternative system of medicine and faith healers. A referral visits to neighbouring state Gujarat was made for palliative elective radiotherapy only to be discontinued a few weeks later due to financial constraints. Throughout the course of treatment and referral, both patient and caregivers were never prognosticated about life-limiting nature of the current illness and end-stage disease.

As part of the management plan, spouse and son of the patient were explained about poor prognosis and life-limiting nature of the disease. They were explained in detail regarding futility of running from one practitioner to another in search of a cure. Their approval was sought before explaining patient about the same. Patient and caregivers opted for the end of life care at home. A team of medical social worker and community physician trained in palliative care was constituted. The team actively established a good rapport with primary care physician and general practitioner in close vicinity to patient residence who were then explained about essence and their role in primary palliation. The team engaged both primary care physician and caregivers in providing home-based palliative care related to oral and general hygiene, relief of constipation, controlling episodes of pain and hematemesis and providing energy-dense food and water to the patient at frequent interval. Once in a week, telephonic communication was done with stakeholders and the fortnightly home visit was carried out to monitor patient condition. Female

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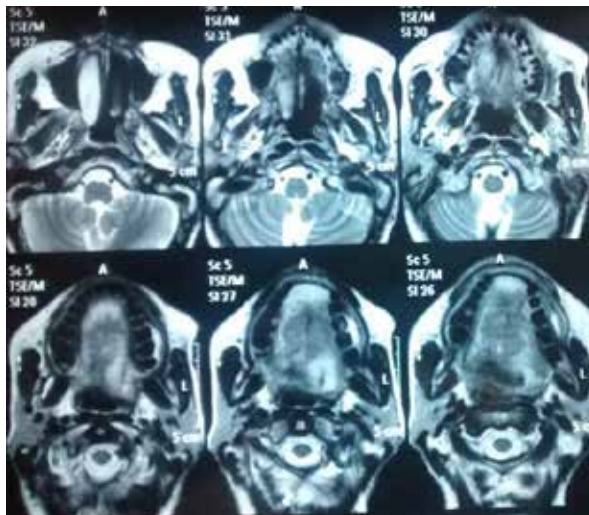


Fig. 1: MRI image of the lesion

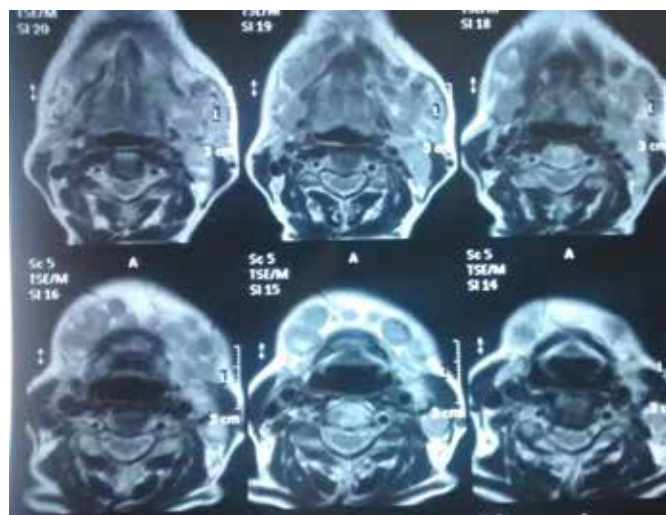


Fig. 2: MRI image of the lesion

members of the family were identified as the main care provider and were actively involved in the treatment plan.

Over the duration of 2 weeks, patient weight improved from 46 kg to 47.3 kg. Improvement in hydration status and oral hygiene was observed. After initial one to two visits to the tertiary centre, the preference of family members shifted to primary care physicians for guidance and support regarding nasogastric feeding, achieving hemostasis during episodes of hematemesis, maintenance of oral and basic hygiene, physiotherapy and issues related to the general well-being of the patient. Patient oral intake and symptoms of pain and constipation reportedly improved in follow up visits. Finally, the patient expired in sleep after 3 months of institutionalizing home-based care. The caregivers conveyed a sense of satisfaction and emotional fulfilment regarding home-based care provided with the support of all stakeholders.

Discussion

Preference of oncologists for aggressive cancer care in form of surgery, adjuvant chemotherapy or radiation at cost of palliative care referral and services at end of life stage is reported.³ Visiting multiple practitioners in and around city reflects poor patient-physician communication and neglected sharing of prognosis as the patient was referred from one health facility to another with the hope of cure and not palliation. Ignored and ineffective communication by hospital-based clinicians is observed to cause

false expectations, side effects and complications among patients “sick enough to die”⁴ and deprives them to prepare for their approaching death.⁵

End-of-life care policy continues to promote dying at home, assuming that caregivers will be able and willing to provide care. The system approach to provide support to family caregivers for managing dying patient is segmented as informational, management and relational continuity of care.⁶ In the current case, establishing a communication network between cancer specialists, community physicians and family physicians provided necessary support to caregivers (management and relational continuity) in taking care of dying patient and prepared both patient and caregivers about approaching and accepting death (informational continuity).

The current case study highlights that communication network between specialist and primary physicians are effective in enabling family physicians or general practitioners in competently providing patient-centric care in the context of family and community and in addressing areas of grief, bereavement and other caregiver issues in terminal illness patients.

The burden of chronic disease including cancers continue to rise in India and other developing economies. Effective role of primary care providers in ensuring cancer care and lack of an integrated system where family physicians are involved in planning and providing services to cancer patients as noted in our set up is reported even in developed countries.⁷

Lack of such collaborative networks in nations especially where palliative care systems are evolving lead to confusion regarding the organization of patient-centric care due to the poor orientation of primary care physicians. Necessary attention and resources to integrate primary physicians in palliative care teams is thus an effective strategy for ensuring continuity of care for cancer patients preferring to die at home.

Conclusion

Terminally ill patient and caregivers present with a diverse need, which extends beyond physical care and control of disease-related symptoms. The focus of healthcare providers on curative and life-prolonging treatment may jeopardize the quality of life of the patient. Institutionalizing care to patient terminal illness requires close coordination between cancer specialists and primary care providers to bridge the gap between demand and supply in establishing essential components of appropriate care.

Learning points

Health systems with evolving palliative care practices must recognize the role of collaborative networks with primary care and family physicians. This will provide a unique platform to establish coordinated cost-effective care of the patient in consultation with cancer specialists. It will also help in bridging gaps towards institutionalizing home-based palliative care. Primary physicians need to be equipped for managing the palliative care of end-stage disease patients. They are the one who can fulfil their role of effective communicator

and care provider for such patients.

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