



Complexities in care of unsalvageable patients

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Abstract: Advanced cancer that is unresponsive to curative strategies in the presence of multiple complicating host and patient factors is a complex matter. The treating physician needs to deal with several unique issues relating to the patient's educational and social background, psychological condition and ethical dilemmas in addition to the management of physical symptoms. In addition, the physician's own understanding of these complexities with prior experience or training and the willingness to contribute time and attention play a huge role. We discuss the various issues in management of an incurable situation, our shortcomings and possible remedies.

Keywords: Palliative care; pain management; psychosocial issues

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Introduction

Inclusion of palliative care along with routine anticancer management has been extensively discussed and the need to train the treating physicians on the various aspects of managing not only physical symptoms but various social, psychological, ethical and moral issues cannot be overemphasized. Cancer care routinely tries to attribute all of these roles to a single caregiver, who may not have adequate insight into these situations at all times. We discuss these issues with reference to a case of incurable malignancy who needed supportive management for various complications, the various psychosocial, ethical, specific management-related challenges and the lacunae in our management that need to be addressed, ideally with training specifically to handle these issues and to reduce communication barriers with patient and caregivers. There are efforts to integrate palliative care into the undergraduate as well as oncology training curricula through certain dedicated programmes and teaching courses though the practical aspects of training and communication skills are lacking (1,2).

Case presentation

A 56-year-old gentleman, a college teacher by profession,

presented to our department with an oral ulcer and bilateral neck nodes. He had been diagnosed with early stage carcinoma buccal mucosa 1.5 years ago, for which he had undergone adequate surgery. In view of low risk early stage disease, no adjuvant therapy had been offered. However, within 6 months of surgery, he developed a 3 cm ipsilateral cervical node for which he underwent radical neck dissection and radiotherapy to ipsilateral neck. Within a year of neck irradiation, he again developed locoregional recurrence, mandating resurgery and adjuvant chemoradiation, after discussion of the risks and expected benefits with re-treatment. He remained disease-free for only 6 months, when he developed bilateral fungating neck node recurrence, painful swallowing and trismus related to fibrosis. He was admitted under our care for pain management and alimentation support. Endoscopy-guided nasogastric (NG) tube insertion was performed. He also suffered from diabetes and hypertension, and control of these comorbid illnesses faltered due to his erratic eating schedule; hence he had to undergo regular monitoring for management of associated complications.

The patient and his family members (wife, son, daughter) were apprised of incurability of his disease, relentless progression and futility of further aggressive anticancer management. A percutaneous endoscopic gastrostomy (PEG) was planned to enable intake at home after his

NG tube got blocked. Neck lesions were managed with local antiseptic dressings. Frequent infections and other complications due to his oral condition and comorbidities were treated symptomatically. After about 1 month of inpatient care, he discharged himself to go home, his son expressing the desire to take him for some alternative therapy. He continued to visit our clinic periodically for follow up, for pain management.

Discussion

We attempted to break up our understanding of his clinical condition, management issues and other aspects including lacunae in our assessment at the time of his treatment. The various aspects are discussed under the following sub-headings.

Psychosocial issues

- (I) Role in family: our patient was the head of the family and was uncomfortable about needing assistance from family members for daily living activities;
- (II) Social Strata: he belonged to upper middle class, and reluctant to share his space with general ward patients, leading to significant anxiety and distress till a private room could be arranged;
- (III) Loss of working days: prolonged absence from his job for treatment disturbed him, and he demanded all suitable measures to enable his speedy return to his previous lifestyle;
- (IV) Body image distortions: change in facial appearance after multiple surgeries and radiation therapy, the fungating neck node as well as inability to talk and swallow were significant distressing factors. He became withdrawn and less eager to communicate with new people;
- (V) Guilt: his only son left his lucrative job overseas to care for his father. Though the son never lamented this fact, our patient wanted to get rid of this guilt by returning to work and regain his “earning member” status;
- (VI) Confusion, disappointment: he was greatly distressed by treatment toxicity and the facial disfigurement after surgery. He found it unacceptable that his condition had become incurable although he had followed all medical advice diligently and had stayed away from his home for treatment for nearly a year.

Due to both the patterns of disease recurrence and the

adverse effects of treatments, patients with head and neck cancer often have a complex and prolonged course of illness that is marked by periods of freedom from disease and symptoms interspersed with bouts of serious illness, debility, and numerous physical and psychological symptoms including pain, dysphagia, weight loss, disfigurement, depression, and xerostomia. Management is best provided by an interdisciplinary team approach. Several psychological aspects affect these patients, including issues such as changes in body image, quality of life, anxiety, and guilt (3,4).

Communication issues

- (I) The patient: the patient was a learned gentleman, quiet but a good listener. He was keen on discussions about his disease and treatment as long as treatment intent was curative, but become anxious and withdrawn when the incurability of his condition was communicated to him. Tracheostomy made speech impossible, and he had to communicate through short handwritten phrases. He wanted us to manage his pain and neck wounds, but did not encourage further discussion with either the treating team or the family. He was intent on returning to work despite full awareness of his progressive disease status and dependence on tracheostomy, impeding speech. He was not in denial since he conveyed to us that he understood his chances but did not want any detailed discussions. He wanted to take his own decisions for management and did not want the family to get too involved;
- (II) The family: the patient was accompanied by his son, an engineer working with a multinational company overseas, during all outpatient visits. He frequently discussed and questioned the aggressive behaviour of disease despite early diagnosis and expressed his suspicion about the correctness of the treatment decisions. After discussing that the decisions were always in keeping with standard management recommendations for his disease stage and physical condition, he did try to explore the option of management at “better centres” abroad if optimum care was not feasible at our centre. On being reassured, he continued treatment, but got angry and disappointed when the disease recurred for a third time, and blamed the physicians for misguiding him. Our efforts always fell short of his expectations. He later sought our opinion on some alternative therapy

that he was contemplating to try. He would often lose hope whenever new complications related to his poor diabetic control or feeding tube leak occurred, stating that our interventions were doing more harm than good, and were preventing him from leaving the hospital and trying out alternative treatments. The patient's wife attributed his deteriorating health to lack of effort by the treating physicians, and her husband's withdrawn demeanour to his discussion with the treating team. She urged us frequently to consult with other "experts" in the field for a possible cure or at least a prolongation of life till the time they could get both their children married. The patient's daughter was actively involved in his day-to-day care and acted as a channel voicing patient's queries regarding his problems and conveying our responses to him. She avoided a detailed discussion on his future course, but asked us if we would be available for guidance and help after he was discharged. She visited the hospital frequently after discharging the patient, and sought help regarding paperwork and pain management-related issues;

- (III) The treating team: as his physicians, it was difficult for us also to accept that he had developed the worst possible course for his disease and initial stage, despite having received the right treatment at the right time. It was challenging to convince the patient and family that nothing had been amiss in his management, and we were doing our best to ensure his comfort. It was frustrating to answer the same questions repeatedly, and we did not quite understand how to make them accept the truth and move forward. It was difficult to control our tempers when we were being blamed for ill-managing the case and not "allowing" them to take him for treatment to a better centre "if we knew we were not as capable". It was hard to decide whether to allow the patient to think he could return to teaching in his school or not, knowing fully well that he would not be able to speak.

Specific management issues

- (I) Endoscopy guided NG tube insertion: our patient had developed absolute dysphagia and was being managed on intravenous (IV) fluids. To allow for enteral nutrition, NG tube was inserted. The tube, however, got blocked and needed replacement in a week. This made the family anxious about management of similar issues at home;
- (II) Tracheostomy: presence of neck edema due to multiple surgeries and reirradiation led to stridor and breathing difficulty, and an emergency tracheostomy was required;
- (III) PEG: since the patient was unable to swallow food due to pharyngeal stricture, and had developed blockage of NG tube once, a PEG procedure was planned for subsequent alimentation. Complications included mild abdominal pain and leak from gastrostomy site, but it resolved within a week and regular feeds could be started (5);
- (IV) Pain management: his pain stopped responding to regular analgesics, and stepping up to tramadol, and later, morphine was required. Other supportive measures such as laxatives, antiemetics, and antacids were added;
- (V) Tracheostomy and wound care: the family members were taught wound dressing and tracheostomy change which they could manage unassisted at home after discharge;
- (VI) Management of hypertension and diabetes: consultations with cardiologist and endocrinologist, dietician consultation and regular monitoring of blood pressure as well as sugars were undertaken and home care was taught;
- (VII) The family members were educated about posture care, mobility, bowel and bladder care to ensure a good quality of life and prevent complications. Physiotherapy assistance to help him learn the importance of daily physical activity, posture, exercises, etc., was sought. The nursing team was involved throughout in assisting the patient with his activities of daily living as well as medication and wound care.

Outcomes and modifications

Each new procedure that the patient underwent led to complications. He developed hyperkalemia whilst on IV fluids before NG tube insertion. The potassium binding resins given through the NG tube blocked it, mandating another NG tube insertion. Meanwhile, he reported having sounds over his upper chest. CT scan showed subcutaneous emphysema from a malpositioned tracheostomy tube. The tube had to be repositioned and switched from a cuffed plastic one to a metallic tube, and the family was coached for changing and cleaning it. Later, when PEG was inserted

to circumvent NG tube related problems, he developed a leak. Although conservative management helped in recovery, initiation of feeds was delayed by a week. Family was counseled and were comfortable once he successfully started a milk-based diet in the second week of PEG insertion.

Frequent drug modifications were required to optimise pain control related to primary disease, treatment-related edema and procedures. His diet was successively changed from IV fluids to NG feeds to gastrostomy feeds, and there were fluctuations in his blood sugar levels that needed monitoring and management with insulin on a sliding scale till a final diet plan could be charted and he could be put on oral hypoglycemic agents.

We were able to manage the patient's physical symptoms despite a few setbacks and his pain and discomfort were addressed adequately. However, there was still evident dissatisfaction in the family and the patient due to our inability to help control the disease. They sometimes felt that we were explaining them regarding the aggressiveness of the disease and complications associated with various procedures to hide our own ineptitude in managing his condition.

Ethical issues

- (I) Disclosure of diagnosis: the patient and family members were already aware of the diagnosis when presenting to our care, and were actively involved in decision-making;
- (II) Information regarding prognosis: available therapy and expected outcomes were discussed. There was difficulty in satisfying queries on the life expectancy specific to his condition and management of end of life;
- (III) Treatment of recurrence: since the patient had faced multiple recurrences and complications of treatment thereof when he first consulted us, there were limited options (chemotherapy/ targeted therapy) even for palliation. The futility in terms of survival prolongation as well as expected toxicity and poor tolerance was discussed;
- (IV) Palliative procedures: since the feeding procedures as well as tracheostomy, performed with the intent of making the patient comfortable were accompanied by their individual complications, their necessity was questioned. The expected benefits and risks had already been discussed before respective procedures

and considering that we were looking at a life expectancy of around 6 months, the procedures did help maintain an ambulatory, minimally assisted lifestyle;

- (V) Resuscitation: a discussion on possible end of life wishes (aggressive resuscitation) and their impact was carried out;
- (VI) Alternative therapy: the family desired our inputs on trying complementary and alternative therapies, which we were unable to opine on with our limited training in those fields.

Alternative strategies to improve care

In the following paragraphs, we attempt to study possible flaws in our understanding and management of the case as well as possible remedies. These could be applied in the general setting according to individual cases.

- (I) Compassion and empathy: it would help to put ourselves in the patient's or the family's shoes and consider things from their perspective before offering our opinions and solutions. We were unable to build a relationship of trust despite all efforts in management and communication. We could not adequately deal with the patient's issues of self-worth, his inability to retain his working status, disorder in the family with the son having to leave his job. Spending more time trying to elicit the family's actual concerns other than those perceived by us on a regular basis might have helped with more effective communication and better acceptance. An observational study conducted in the Netherlands analysed patient and physician questionnaires and audiotape analysis of communication regarding daily activities, emotional functioning, pain, and fatigue during an outpatient consultation, and found that in 20–54% of the consultations in which patients were experiencing serious health related quality of life (HRQOL) problems, no time was devoted to discussion of those problems. Despite increasing recognition of the importance of maintaining patients' HRQOL as a goal of palliative treatment, the amount of patient-physician communication devoted to such issues remains limited (6);
- (II) Psychiatric assistance: though our patient appeared depressed, we never sought a formal psychiatric advice. Consultation with experts who may be

better capable of managing problems relating to mood and coping capabilities may help allay anxiety and fears. Psychotherapy, behavioural therapy and pharmacological management of depression may go a long way in improving the patient's QOL;

- (III) Peer support groups: inclusion in groups of patients suffering from similar problems may help the patient grasp his own condition better and may be therapeutic;
- (IV) Return to work: our patient was keen to return to work and our scepticism was discouraging him from achieving a suitable lifestyle. We could have discussed possible achievable goals in the setting of his disabilities and life expectancy, and handled the situation in a more optimistic light;
- (V) Complementary therapies: we should not have discouraged the patient from trying out alternative therapies. We could not offer cure but we could have urged them to try out any further treatments after fully ascertaining the reliability and authenticity of the source. A word of caution instead of cynicism would have sufficed;
- (VI) Spiritual advice: discussion with the family on any perceived need of talking to a spiritual counsellor should have been undertaken, and their wishes on this issue respected.

Possible solutions

Physician insight

The diagnosis of cancer scares even the most learned and sturdy people. The grief of not being able to control the disease despite vigilance and aggressive management, to see one's family disintegrate because of the strain and to lose one's self-worth and become dependent on a handful of machines for sustenance cannot be expressed adequately. This needs to be understood while managing people with such conditions. Management of pain and individual symptoms such as constipation, weakness, etc., is important but we also need to address the psychosocial issues such as anxiety and fear through effective communication. Each person's individual needs may be different from our perceptions based on their prior experiences; thus, it is important to elicit problems bothering them so that they could either be mitigated by suitable intervention or healed simply by a compassionate hearing. A holistic approach addressing emotional, psychological and spiritual issues and

appropriate medical intervention and counselling wherever indicated may go a long way in fulfilling the goal of effective palliative care.

Professional knowledge and skills

Physical

Effective pain management is hugely satisfying, even if it entails the regular use of NSAIDs and strong opioids. Secondly, even the simplest of procedures (NG tube insertion, tracheostomy) may be accompanied by complications which may cause more distress and anxiety than relief, and the pros and cons of these procedures need to be weighed and discussed before implementation. Careful watch for possible complications is warranted. Mobilization of the patient, care of bowel and bladder is important to nurture a sense of well being and to overcome fatigue (7).

Psychosocial

It is important to give attention to the smallest of fears. A realistic attitude towards expected outcomes, encouragement for self-reliance and assistance in devising a course of action that normalises family life as far as possible may help them cope more effectively. Vigilance for any hints of anxiety and depression and assistance from psychiatric counselling or other support groups is key to a meaningful well-adjusted life. Giving uninterrupted time and a compassionate hearing to their concerns even if tangible solutions do not exist may be therapeutic, and supercede any physical interventions in bringing satisfaction and peace (8).

Spiritual

The patient should be encouraged to engage in activities that bring them peace and happiness, including meeting with near and dear ones. Any ongoing conflicts within the family leading to stress should be addressed. Patient's religious beliefs and conventions should be respected. The patient may be encouraged to read spiritual texts or even consult with a spiritual counsellor if he shows such an inclination. It is important not to pass our own judgments regarding patient's actions or beliefs; in case of disagreement, one's opinion may be volunteered but final decision on any course of action should be left to the patient and his family. Addressing unmet goals through counselling, boosting one's self worth through honest encouragement and being open to communication may prove better than any available physical therapies (9).

Policy and innovations in practice in the clinic

The need for integrating palliative care into routine cancer management has been long perceived but is still far from

being effectively addressed. There is a need to understand that people involved in cancer diagnosis and therapy, whether curative or otherwise, need to be well versed with the principles of pain management and symptom control. Effective communication and an eagerness to help the ailing by either medical interventions, lending a patient ear, counselling and expert guidance or spiritual advice constitute the very core of effective palliative care (10,11).

Government bodies need to understand the importance of an all-encompassing health care. The stress of having to miss work and still to arrange for finances for treatment stops many from seeking timely treatment. Health insurance needs to be integrated into the system to enable effective management of cancer and related symptoms at all stages and for all individuals irrespective of the intent of therapy being curative or palliative. The patients have a right to know of their diagnoses and expected outcomes with available treatments. These should be discussed several times during the course of treatment. Multimedia clips on routine procedures, special interventions, precautions that the patients have to follow in their respective treatment courses may help in getting the message across more effectively. A medical social worker and a psychiatric counsellor or psychologist need to be involved as an integral part of the palliative care team to address patients' concerns.

Free drugs and provisions should be made available either through the hospital or health insurance schemes. Toll-free helplines that employ trained counsellors and address patients' or families' concerns regarding psychosocial issues need to be made available and widely advertised. Cancer survivors and other motivated volunteers may help guide the patients through the apparently insurmountable maze of testing and treatment as seen in any government hospital. This would help reduce anxiety and improve patient confidence in the healthcare system. Education regarding end-of-life care with specific focus on addressing all the associated fears through the combined efforts of a psychiatrist and a spiritual counsellor may allow better adjustment of the patient and family. Special groups such as stoma societies, speech and language therapists, peer support groups, websites and social organizations comprising of people facing the same challenges coming together to discuss their problems and find their solutions through mutual dialogue, necessary guidance, financial support, etc., need to be encouraged and supported by governmental and non-governmental agencies (12,13).

Introduction of non-profit organizations dedicated to supporting and advancing compassionate health care

delivery, provides hope to the patient, support to caregivers, and sustenance to the healing process with a responsibility to provide grieving families with support and care; care that goes beyond the death (14).

Above all, there is a need to understand and place the patient's needs and wants before our zeal for unnecessary interventions that could bring more harm than comfort. This is very well summed up in one of the aphorisms regarding patient care by the famous American TB physician Edward Trudeau, "To cure sometimes. To relieve often. To comfort and support always".

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Footnote

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