Palliative Medicine Grand Round

Beheaded Souls –
The psychosocial distress faced by head and neck cancer patients

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ABSTRACT
Despite the advances in tumour targeted surgery, radiotherapy and chemotherapy, the palliative care needs of patients with head and neck cancers remain significant. The complex psychological and spiritual issues are often underestimated and underaddressed. We presented three patients with head and neck cancer, and recent studies in this area were reviewed.

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Story of Mr. A
Mr. A presented with hoarseness of voice in 2003 when he was 60. He was diagnosed to have laryngeal cancer with radiotherapy done at that time. He remained in remission until 2007. Tracheal stent was inserted as he was found to have recurrence below the vocal cords. The tumour continued to infiltrate and repeated stent revisions were required. Finally the mass grew around the trachea at the level of stent, inseparable from the lower cricoids cartilage and inferior pole of thyroid gland. It was decided that no further surgical nor oncological intervention would be possible.

Two days later he attempted suicide by cutting his wrist in the ward toilet. Bedside exploration and suturing was performed by the orthopedic surgeon. He was diagnosed as suffering from “situational reaction” by the psychiatrist. Tracheostomy was performed in view of potential airway obstruction, and he was transferred to our unit for palliative care.

An interview was arranged to explore the meaning of his act of deliberate self-harm. He expressed hopelessness and frustration after hearing that no more stent revision could be performed. He felt helpless after being told that nothing could be done to help him except “referring him to a hospice ward”. In fact he felt helpless that he might suffocate to death. His discomfort and mood were improved after placement of tracheostomy. He had intermittent episodes of suffocation due to blood clots, which could make him desaturate and cyanosed. He did not require any antidepressant. He was put on palliative sedation with his and his family members’ consent three months later, due to irreversible tracheostomy blockage by tumour. His morale remained positive during the last months in his journey with palliative care.

Story of Mr. B
Mr. B enjoyed good past health until 2004. He presented with left jaw swelling. Excision showed basal cell carcinoma. He received left supraomohyoid functional neck dissection and then radiotherapy. Tumour recurred in 2006 and he received radical neck dissection with another course of adjuvant radiotherapy. His disease recurred in 2007. He visited traditional Chinese medicine practitioner for follow up until December of 2008. He returned to his oncologist because of progressive neck pain with increasing discharge. He requested euthanasia because he thought that there was no further intervention which could alleviate the symptoms. He was referred to our Palliative Care Team for assessment.

During the first consultation, he admitted that his mood was low and affected by uncontrolled pain. The pain was neuropathic in nature. Examination showed a smelly fungating mass larger than 10cm encasing his neck with contact bleeding. Amitriptyline was started, both for low mood and neuropathic pain. He was also referred to Community Nursing Service for home dressing of the wound.

A few weeks later he was admitted for difficulty in swallowing. During the ward round he requested our assistance to send him to the Netherlands for euthanasia. Further exploration found that he worried he had become a burden to his sisters, who were very helpful and supportive carers during his illness. He also worried the mass would erode into his neck, causing severe bleeding. We took the opportunity to discuss...
advanced care planning with him and his sisters. Emergency palliative sedation was agreed in case there was sudden carotid artery burst out. Respite hospice service was also suggested if his sisters were unable to cope and feeling overburdened. His worry of being a burden was reassured by his sisters also. He also decided not to initiate artificial nutrition by nasogastric tube or percutaneous gastrostomy in case oral feeding was not possible.

His morale and mood improved after the in-depth discussions. He was readmitted on a few more occasions later; some were for malignant wound care, some were for respite care. He finally passed away few months later with his family accompanying him at the end.

**Story of Mr. C**

Mr. C underwent partial glossectomy and selective neck dissection in 2007 due to squamous cell carcinoma of tongue at age 64. He received conformal radiotherapy but the tumour recurred few months afterwards. He then received modified radical neck dissection with right submandibular sialoadenectomy. After that he received another course of radiotherapy. Three months later he was found to have jaw recurrence. The positron emission tomography (PET) showed loco-regional recurrence and lung metastasis. He then received palliative chemotherapy starting from September 2009.

Mr. C attempted suicide by jumping from height in mid February 2009. Fortunately he was stopped by his social worker during a scheduled visit. He admitted that he trapped himself in electrical wires and suffered burns, causing multiple blisters and strangulation marks over the limbs. He was sent to hospital with amputation of left index finger and left thumb performed due to full-thickness burn complicated by infection. He was diagnosed to have depression by psychiatrist with sertraline and lorazepam started. He was put on nasogastric tube for feeding as the tumour had obstructed the whole oral cavity. Surgical resection was not possible and patient refused palliative radiotherapy. He was sent to our palliative care unit for further care.

Mr. C was a chronic smoker and drinker. However he lived alone and had no close relatives in Hong Kong. Upon arrival he was already bed-ridden and cachexic. There were multiple strangulation marks around his hands. The fungating tumour was obstructing the oral cavity. He could only communicate by nodding or shaking his head. Poor hygiene was noticed. We started morphine for pain control as he indicated severe cancer pain. We also applied metronidazole solution over the wounds. Our medical social worker contacted the NGO who would provide funeral service to patient. He passed away in the following morning.

**Beheaded Souls, are we ready?**

The physical and psychological needs of head and neck cancer (HNC) patients are challenging. The palliative care needs of these patients are not decreased by advances in the surgical and oncological fields.

There are unique but under-addressed psychological burdens faced by HNC patients.

1. Pre-morbid adaptive coping deficits

   Smoking and alcohol use increase the prevalence and mortality of head and neck cancer. Duffy et al. screened 973 head and neck cancer patients, 46% were positive for depressive symptoms, 30% smoked and 16% were problem drinkers. Depressive symptoms and smoking status were associated with negative quality of life. Problem drinking is more prevalent among HNC patients than the general population (16% vs. 8.5%). Alcohol use itself increases the mortality of HNC patients. Over one third of patients continue smoking even after the diagnosis.

2. Higher reported rates of suicide

   Analysis from the data of Surveillance, Epidemiology, and End Results (SEER) program found that HNC patients had higher suicide rates. Kendal found that among male cancer patients, HNC (p<0.001) and myeloma (p=0.02) had higher completed suicide rates. It was found that among HNC patients, being male, older, surgery being contraindicated, histology of cancer being of higher grade, suffering oropharyngeal cancer will have increased hazards ratio of completed suicide. Misono et al. studied 3,594,750 patients diagnosed with cancer from 1973 to 2002. They found that head and neck cancer patients had higher suicide rates comparing with the other cancer types as well as the general population. While lung cancer and stomach cancer patients had the highest suicide rates with standardized mortality ratio (SMR, general US population suicidal rate =1) 5.74 and 4.68 respectively, oral cavity and pharyngeal cancer, and laryngeal cancer ranked third (SMR = 3.66) and fourth (SMR = 2.83) respectively.
3. Unique barriers of communication and emotional expression

HNC can distort facial expression, which is the most important part of emotional expression. The cancer itself, treatment and its complication can affect voice production. Patients can become dysphasic or aphasic. Tracheostomy, if performed, may further hinder the patients’ ability to communicate.

4. Unique stress of illness

The line between curative and palliative intervention in HNC is blur. The uncertainties make care planning in HNC patients difficult and may even produce ethical dilemmas. A Japanese study reviewed the dying process of 55 terminal HNC patients retrospectively and reported that 30% patients died suddenly, mainly due to haemorrhage. These illness trajectories pose significant psychological stress on our patients.

More importantly, facial disfigurement and dysfunction will produce severe psychological trauma to HNC patients because of its visibility. The face has its specific role in human psychological being (see Table 1) and post HNC surgery patients often reported suffering psychological impairment due to distorted body image (Table 2). Dropkin defined body image as the perception of one’s body as a physiologic-psychologic-social unity, which is dependent upon: (i) individuals’ memory of his pre-surgical appearance and function, (ii) idealized self-appearance and function and (iii) his current status (Table 3). Callahan uses the concept of “internal conflicts vs. external conflicts” to describe the psychological distress. The external conflict is due to the large unsightly, oozing and smelly tumour which distorts the individual’s appearance. The internal conflicts stem from the heightened sense of shame, self-consciousness and hyper-vigilance. HNC patients are highly sensitive to perceived stares by passers-by.

**Management of the psychological distress of HNC patients**

The fundamental step of assessment and management of psychological distress in HNC patients is ASKING. The multi-disciplinary team, involving physicians, nurses, physiotherapists, occupational therapists, speech therapist, dietitians, social workers, spiritual counselors, volunteers and the larger social network is essential. The family and patient should be involved in managing the psychological distress. General intervention includes good symptom control and treating any associated depression is essential. Therapy should focus on patients’ sense of hopelessness and fracture of dignity. Discussions surrounding spirituality by skilled spiritual counselors would be helpful. Communication strategies and social network should be enhanced. Advance care planning with the patient may help to reduce patients’ uncertainty.

**Table 1. Role of face**
- Communicates ideas, perception, intensity of emotion, self-reflection and awareness
- Reflects self-concept and self-esteem
- Reflects feeling about the body
- Communicates pride or shame in one’s appearance
- Mirrors the lifestyle chosen
- Radiates one’s personality style

**Table 2. Psychological distress reported by patients after HNC surgery**
- Feeling of distress
- Negative changes in self-image
- Loss of self-esteem
- Perceptions of limited attractiveness
- Diminished feelings of sexuality due to embarrassment
- Increased isolation

Advances in technology have made communication easier. A survey found that one-third of head and neck cancer patients are interested in e-mailing their clinicians but only 9.5% reportedly did so. The most common issues addressed would be symptom management and prescription refills. However, direct e-mail communication between patients and health care staff is not popular in Hong Kong. In the Netherlands, an information support system is set up for the head and neck cancer patients to facilitate communication between professionals and patients. Patients can also contact other fellow patients and search for information related to their illness through the system. In case there is change in symptoms, the system assists in early detection by screening using tailored questions.

Recent studies have focused on the role of prophylactic antidepressants as well as behavioural modulating antidepressants in HNC patients. Lydiatt et al. randomized 23 non-depressed, non-psychotic, non-suicidal HNC patients undergoing treatment to either placebo or citalopram. After treatment for 12 weeks, only 2 out of 12 patients receiving citalopram met the
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Table 3. Disfigurement/ Dysfunction Scale

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<th>A. Disfigurement</th>
<th>B. Dysfunction</th>
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<tr>
<td>Minor 1. Radial Neck Dissection (RND)</td>
<td>1. Loss of smell</td>
</tr>
<tr>
<td>2. Cheek Resection with Forehead Flap Repair</td>
<td>2. Unilateral hearing loss</td>
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<tr>
<td>3. Total Parotidectomy with Facial nerve Sacrifice</td>
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<tr>
<td>Moderate 4. Total Laryngectomy</td>
<td>3. Impaired mastication</td>
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<tr>
<td>5. Bilateral Radical Neck Dissection</td>
<td>4. Speech impairment</td>
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<tr>
<td>6. Orbital Exenteration</td>
<td>5. Unilateral loss of vision</td>
</tr>
<tr>
<td>7. Hemimandibulectomy with RND</td>
<td>6. Impaired salivary control</td>
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<tr>
<td>Severe 8. Nasal Amputation</td>
<td>7. Impaired deglutition</td>
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<tr>
<td>9. Anterior Partial Mandibulectomy</td>
<td></td>
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<tr>
<td>10. Segmental Mandibulectomy with RND</td>
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<tr>
<td>11. Orbital exenteration with Radical Maxillectomy</td>
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Duffy et al. randomized 184 HNC patients into either usual care or a nurse-administered intervention protocol, which included cognitive behavioural therapy for 9 to 11 sessions plus appropriate medication. All participants were either smokers, problem drinkers or depressed patients. Bupropion would be used if the subject was either depressed or had been a smoker in whom the nicotine patch had failed. They found that the intervention group had decreased smoking rates by 50% (47% vs. 31%, p<0.05). The authors also claimed that there were clinically important but statistically insignificant reduction in alcohol use and depressive symptoms.

**Conclusion**

According to Eric Cassell, the obligation of physicians is to relieve human suffering. HNC patients face unique illness trajectories with specific problems affecting their intactness. How can we preserve human integrity for these beheaded souls?