

## Review Article

# A Good Ending—Holistic Care for Patients with Head and Neck Cancers

Hong-Wen Chen<sup>1,2</sup>, Yu-Jen Chen<sup>1</sup>, Yi-Shing Leu<sup>2,3</sup>, Chung-Ji Liu<sup>2,4</sup>, Yi-Fang Chang<sup>2,5</sup>, Chun-Kai Fang<sup>2,6</sup>, Hui-Ching Liu<sup>6</sup>, Yuen-Liang Lai<sup>1,7,8\*</sup>

<sup>1</sup> Department of Radiation Oncology & Hospice Center, Mackay Memorial Hospital, Taipei, Taiwan

<sup>2</sup> Mackay Medicine, Nursing and Management College, Taipei, Taiwan

<sup>3</sup> Department of Otorhinolaryngology, Mackay Memorial Hospital, Taipei, Taiwan

<sup>4</sup> Department of Oral & Maxillofacial Surgery, Mackay Memorial Hospital, Taipei, Taiwan

<sup>5</sup> Department of Medical Oncology, Mackay Memorial Hospital, Taipei, Taiwan

<sup>6</sup> Department of Psychiatry and Center of Suicide Prevention, Mackay Memorial Hospital, Taipei, Taiwan

<sup>7</sup> The Graduate Institute of Humanities in Medicine and Shuang-Ho Hospital, Taipei Medical University, Taipei, Taiwan

<sup>8</sup> General Education Center, Yang-Ming University

### Abstract.

Terminal head and neck cancer is one of the most distressing ways a person may die as it affects the patient's quality of life widely. The comprehensive multidisciplinary management of patients' physical, psychosocial, and spiritual needs will enhance the possibility of patients and their families obtaining the best quality of life. This includes adequate symptom control, being treated as a whole person and achieving a sense of completion. By such holistic care, patients will experience a peaceful ending.

**Keywords :** Head and neck cancers, Hospice palliative care, Quality of life, Good death

## 綜合評論

### 頭頸部癌症患者的安寧療護

陳虹汶<sup>1,2</sup> 陳裕仁<sup>1</sup> 呂宜興<sup>2,3</sup> 劉崇基<sup>2,4</sup> 張義芳<sup>2,5</sup> 方俊凱<sup>2,6</sup> 劉惠青<sup>6</sup> 賴允亮<sup>1,7,8\*</sup>

<sup>1</sup> 馬偕紀念醫院 放射腫瘤科及安寧療護中心

<sup>2</sup> 馬偕醫護管理專科學校

<sup>3</sup> 馬偕紀念醫院 耳鼻喉科

<sup>4</sup> 馬偕紀念醫院 口腔顎面外科

<sup>5</sup> 馬偕紀念醫院 血液腫瘤科

<sup>6</sup> 馬偕紀念醫院 精神科

<sup>7</sup> 台北醫學大學醫學人文研究所及雙和醫院

<sup>8</sup> 陽明大學通識教育中心

### 中文摘要

末期頭頸部癌症對生活品質的廣泛影響，使其成為最痛苦的死亡之一。完整而全方位的照顧，針對患者身心靈需求的提供，特別是足夠的症狀控制、整體性的評估及

治療，使病患得到身心靈的整合，將可大幅提高病患及家屬的生活品質。透過全人照顧的方式，善終將是可以期待的。

**關鍵字:** 頭頸部癌、安寧緩和醫療、生活品質、善終

## INTRODUCTION

Hospice care is an active total care of patients with progressive, far-advanced disease and a short life expectancy to achieve the best quality of life for patients and their families through the control of physical symptoms, psychosocial and spiritual problems [1]. The model of care is holistic, since the experience of patients is dependent on the interaction of physical, psychological, social, and spiritual factors. Because every patient is unique, optimal care needs to be individually tailored, though patients with the same cancer may face similar problems. There is currently little material available about the care of the final phase of life in patients with head and neck cancer.

In spite of extensive progress in oncology treatment, cure rates for head and neck cancer have only increased slightly during the past few decades. As local control has improved with the use of multimodality therapy, failure patterns have changed, with an increased proportion of patients who fail distantly. This is the cause of death in nearly a third of patients [2, 3]. Second primaries in the head and neck region are common, in perhaps one in eight patients, and are associated with a poor prognosis [4]. In cases of recurrent or residual disease of head and neck cancer, the efficacy of salvage treatment is mostly limited, and only effective for a short period of time [5-7]. Due to disease-related factors (recurrent tumor site, fungating malodorous tumors, body-image change), the adverse

effects of treatments (morbidity), and patient-related factors (psychological problems, substance dependence, lack of economic or family support), patients with head and neck cancer present particular challenges to health care professionals. Thus, management of this disease in the terminal phase is best provided by an interdisciplinary team.

In this article, we review the literature on the terminal phase of head and neck cancer patients, and provide information about the specific physical, psychosocial, and spiritual distress faced by such patients and their families, as well as the challenging complex problems encountered by professional care givers. This may enable each member in a comprehensive care team to cooperate well in the provision of real “total” care for those patients.

## PATIENTS

Terminal head and neck cancer is one of the most unpleasant ways a person may die [8] since the structures of the head and neck are disfigured by tumor, previous surgical interventions and side effects of radiotherapy, and the dying process is slow, lingering, and painful [9]. Most patients want to experience a ‘good death’. Though the concept of a good death varies between individuals, especially between health care professionals and patients [10-12], the maintenance of dignity, freedom from distressing symptoms, and a comfortable death have always been considered top priorities by patients and their families when they recognize that their disease is incurable [12-15]. Steinhauser et al. identified several factors important for a good death, including adequate symptom control, clear decisions about management, being treated as a ‘whole person’, making preparation for death, and achieving a sense of completion [16]. The following

---

\*Corresponding author: Yuen-Liang Lai M.D.

\*通訊作者：賴允亮醫師

Tel: +886-2-28094661 ext.3142

Fax: +886-2-28201095

E-mail: enochlai49@yahoo.com

discussion relates to the holistic care of patients with terminal head and neck cancers.

## PHYSICAL CARE

### Adequate Symptom Control

Patients with recurrent or advanced head and neck cancer report a median of six symptoms (range 2-12 symptoms). Pain, weight loss, feeding difficulties, dysphagia, respiratory symptoms, xerostomia, oral thrush and communication difficulties were the major problems [17, 18]. In cases of locally advanced disease, most patients suffer from disgusting malodorous secretions from fungating tumor masses, difficulty in wound care due to easy bleeding, and social withdrawal due to embarrassment. During the terminal phase, recurrent bleeding episodes, airway obstruction, and breakthrough pain are the main causes of emergency admission [19]. The following discussion relates to the management of special problems in the terminal phase of the illness.

### Pain

A recent review showed that the prevalence of pain was over 50% in all cancer types, while the highest prevalence was found in head and neck cancer patients (70%) [20]. Usually, patients suffer from more than one site of pain [21], which is often mixed nociceptive (bone, skin, muscle) and neuropathic due to nerve invasion or pressure by the tumor, lymphoedema, soft tissue inflammation, or infection within a restricted fascial space. The appropriate management of pain involves identifying the etiology to enable definitive interventions. Nociceptive pain usually responds well to opioids and NSAIDs, while neuropathic pain does not. Adjuvant analgesics are used in the management of neuropathic pain when response to opioids and NSAIDs is poor. They include anticonvulsants, antidepressants, and ketamine. Steroids are used to reduce swelling and pressure effects on nerve endings. Hypofractionated radiotherapy, e.g. 30 Gy in

5 fractions over 2 weeks can relieve pain by reducing tumor mass effects [22], and is also useful for drying a fungating, discharging wound. Antibiotics can contribute to analgesia by reducing pressure due to infection in a restricted fascial compartment [4]. Local delivery of analgesics via an implanted catheter, neuroablation, or neurolytic procedures can be useful in selected patients. Non-pharmacological interventions, such as transcutaneous electrical nerve stimulation, acupuncture, aromatherapy, reflexology, as well as relaxation management, may help to reduce the suffering [4].

“Total pain”, defined as suffering that is related to, and the result of, the person's physical, psychological, social, spiritual and practical state, should be considered if the daily dose of opioids increases rapidly or the expression of pain does not correlate with the disease status [23]. Thus, the dose titration of opioids should not be evaluated only by a pain score; any factors that may contribute to lowering the pain threshold also need to be assessed and managed (such as psychological or spiritual suffering).

### Emergencies

According to the report of Forbes, nearly half of patients with head and neck cancer die as a result of a gradual deterioration in their disease, while 15% patients may die from an acute complication of their disease (e.g. airway obstruction and massive hemorrhage) [18]. The following discussion relates to the management of these two emergencies in the terminal phase of the illness.

When there is a risk of airway obstruction, the management plan should be based on the patient's general condition, current disease status, and personal wishes. If the patient is at the end of life or does not accept intensive management, various interventions should be used to relieve the patient's respiratory distress or anxiety and to support relatives [24]. Intravenous corticosteroids and subcutaneous opioids or benzodiazepines (e.g. midazolam) can alleviate the

distress. Midazolam, a sedative drug, can prevent panic attacks and break the vicious cycle of dyspnea and anxiety.

When there is a risk of hemorrhage, the management plan should consider the patient's general condition, the etiology of bleeding (normal vessels or tumor vessels), the bleeding amount, the interval from any previous episode, and the risk of death [4]. Although life-threatening hemorrhages are a relatively rare cause of death in head and neck cancer, they can be frightening to patients, their families (especially if children are present), care givers, and new staff [25]. If there is a high risk of massive hemorrhage, it is generally appropriate to inform the care givers and explain the role they may play during acute bleeding, since calm care givers are a good support for the distressed patient.

Massive hemorrhages usually recur. They are therefore a sign of impending death. At this point, clear communication with patients and families is important so they understand that this is their final opportunity to be with the patient. In such a situation, pharmacological interventions depend on the personal goals of the dying person. For example, the appropriate doses of opioids and midazolam depend on how lucid the patient wants to be. The role of blood transfusion and intravenous fluids must be carefully considered since they may hasten the next episode of hemorrhage.

## Depression

Studies have shown that 20-50% of patients with head and neck cancers may suffer from depression after diagnosis [26-28]. In addition, nearly two thirds of relatives claimed the patient was depressed [29]. Diagnosis can be difficult, since the physical signs, such as anorexia, insomnia, and fatigue, are also prevalent in cancer itself [4]. Whether these symptoms are an episode of major depression or an adjustment disorder, antidepressants may help [30]. For example, patients with anorexia and weight loss may benefit from mir-

tazapine [31]. Psychiatric consultation is needed. The risk of suicide should be carefully assessed.

## Anxiety

Anxiety may be general or related to specific fears of specific symptoms, such as breakthrough pain and tumor bleeding, or related to uncertainty about the future. Patients with impaired quality of life related to anxiety may benefit from medications such as benzodiazepines or selective serotonin reuptake inhibitors.

Though psychotherapy and support groups may be beneficial to patients with head and neck cancers in other countries [32], they are not convenient in Taiwan. Physicians can assist patients by encouraging them to talk about their fears, anxiety, or uncertainty while at the same time offering consistent support and establishing possible goals for further management.

## Facial Disfigurement

The psychosocial problems reported by people with a facial disfigurement can be defined primarily in terms of social difficulty [33]. Accounts of people's difficulties through the studies of investigators [34] as well as disfigured individuals themselves suggest that facial disfigurement is a major source of distress [35] which leads to psycho-social difficulty. The result is social anxiety and withdrawal, plus increased financial hardship for the family. The patient's role in the family may be seriously affected. In advanced progressive head and neck cancer, rapid tumor growth may be accompanied by distorted facial appearance, weakness and a shrinking social world. The changed facial appearance may become a barrier between the patient and his/her family, especially their children. Hospice care includes families as well as patients. The images of patients during their final phase of life may be deeply embedded in families' memories, and cause great concern to all parties. Patients may refuse to allow their children to see certain treatment procedures, e.g. wound care. The higher prevalence rate of head and neck cancer in young people, especially in those

of mixed race, and its potential psychological effects are worth further investigation. For very small children, the dramatic disfigurement of their dying parent sometimes makes them ambivalent. They may be longing for intimacy but at the same time feeling scared and show avoidance behavior. After several attempts to get close, they may finally decide to maintain a watchful distance from the parent. In this situation, the hospice care team can help these children by using special skills, e.g. play therapy, art therapy, or sharing experiences among siblings. The “last image” of the parent is quite important to both the patient and their child. Under some circumstances, the child is allowed to visit their parent only when the parent is on the point of death. Skillful mortuary care and appropriate guidance are often helpful to attenuate the grief reaction of loss.

## PSYCHOSOCIAL CARE

### Being Treated as a ‘Whole Person’

A recent study from the point of view of surviving relatives showed that medical treatment during the palliative stage was sufficient in most cases. However, the majority of patients had more need for psychosocial support in addition to physical support. Moreover, patients who did not receive spiritual support may judge the psychosocial support from the care team as less satisfactory [29].

As mentioned in the comments about total pain, the experience of patients is dependent on the interaction of physical, psychological, social and spiritual factors. It is not unusual to see that the daily dose of opioids decreases surprisingly after the patient has found meaning in his suffering, or some psychosocial burden has been laid down.

Another example is the care model for body image change. The body-image care model presented by Price, a useful triangle of body reality, body presentation and body ideal offers a tool for working on improving body image [36]. Though appearance (body

reality) may not be improved due to the progressive disease, wound care and suitable shielding can improve body presentation. Psychosocial support delivered by team members and perhaps the presentation of role models can improve body ideal. As reported by Clarke, nurses are in a particularly strong position to support those patients since they care for the wound day by day. The behavior and attitude of nurses towards the wound usually affect the patient’s self-acceptance. This means that nurses may provide valuable psychosocial support to patients through their daily physical nursing care [33].

Many patients with head and neck cancer will have a history of betel nut, tobacco, and alcohol use, which may indicate poor economic status, poor family and social supports, and sometimes poor coping strategies [4]. The focus of psychological care is to discover the patient’s major concerns, and which concerns need to be addressed. Lack of a plan may be related to anxiety in the patient and their family. To set an achievable and appropriate goal of life based on patients’ wishes, through truthful honest discussions with patients and their families, is a good way for them to cope with their progressive disease. For patients with disease deterioration, professionals should encourage discussion with patients or their family about advanced care planning, such as the goals of management (prolongation of survival or palliation), end-of-life decision-making, and the preferred place for dying. As reported by Ledeboer, many relatives of patients found that patients who were better informed about the stage of dying perceived better psychosocial support and were better prepared for death [29]. Though different cultures may have divergent approaches at this point, truthful discussions about prognosis are important, so the family can understand that the patient has begun to enter the last phase of life and can grasp the opportunity to deal with unfinished business, such as thanking, forgiving, and goodbyes.

## SPIRITUAL CARE

### Achieving a Sense of Completion

Though each individual has spiritual needs, people who are facing death or terminal illness may experience deep spiritual needs, such as the need to search for meaning in life or meaning in their suffering, the need to be connected with others or a higher being, the need for integration and a sense of completion, and the need for hope. This search for meaning, for connection, and for integration can be a transformative experience for patients, their relatives, and professional care givers as well. Awareness of individualized spiritual needs as well as spiritual distress calls for a person-centered, flexible approach. Optimal quality of life and a secure environment, such as the relationship between patient and professional caregivers, may facilitate the unfolding of the patient's inner healing process [37]. As Saunders stated, 'the way care is given can reach the most hidden places and give space for unexpected development [38].

## CONCLUSIONS

Patients with head and neck cancers experience a complex of physical, psychosocial, spiritual distress throughout the disease course, from diagnosis till the end of life. Through holistic care by a multidisciplinary team, the suffering of patients and their families can be diminished as much as possible and a comfortable and peaceful end of life is achievable.

**ACKNOWLEDGEMENT:** We thank Dr. Doug Bridge, the senior lecturer at the Department of Palliative Care, University of Western Australia, for assistance in preparation of the English manuscript.

## REFERENCES

1. World Health Organization: Cancer Pain Relief and Palliative Care. Technical Report Series 804. World Health Organisation, Geneva.
2. Taneja C, Allen H, Koness RJ, et al. Changing patterns of failure of head and neck cancer. **Arch Otolaryngol Head Neck Surg** **128(3)**: 324-7, 2002.
3. Yao M, Nguyen T, Buatti JM, et al. Changing failure patterns in oropharyngeal squamous cell carcinoma treated with intensity modulated radiotherapy and implications for future research. **Am J Clin Oncol** **29(6)**: 606-12, 2006.
4. Watson M, Lucas C, Hoy A, et al. Oxford Handbook of Palliative Care. Oxford; 2005.
5. Robbins KT. Is high-dose intensity intraarterial cisplatin chemoradiotherapy for head and neck carcinoma feasible? **Cancer** **103**: 447-450, 2005.
6. Teymoortash A, Bien S, Dalchow C, et al. Selective high-dose intra-arterial cisplatin as palliative treatment for incurable head and neck cancer. **Onkologie** **27**: 547-551, 2004.
7. Anscher MS, Kong FM, Andrews K, et al. Treatment of recurrent and advanced stage squamous cell carcinoma of the head and neck. **Semin Radiat Oncol** **14**: 190-195, 2004.
8. Herzon FS, Boshier M. Head and neck cancer—emotional management. **Head Neck Surg** **2**: 112-118, 1979.
9. Pashley NR. Practical palliative care for the patient with terminal head and neck cancer. **J Otolaryngol** **9(5)**: 405-11, 1980.
10. Clark J. Freedom from unpleasant symptoms is essential for a good death. **Br Med J** **327(7408)**: 180, 2003.
11. Walter T. Historical and cultural variants on the good death. **Br Med J** **327**: 218-20, 2003.
12. Steinhauser KE, Clipp E, McNeilly M, et al. In search of a good death: observations of patients, families and providers. **Ann Intern Med** **132**: 825-32, 2000.
13. Lichter I, Hunt E. The last 48 hours of life. **J Pall Care** **6**: 7-15, 1990.
14. Good care of the dying patient—American Medical Association Council on Scientific Affairs. **JAMA** **275**: 474-8, 1996.

15. Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life. **BMJ** **326**: 30-4, 2003.
16. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians and other care providers. **JAMA** **284**: 2476-82, 2000.
17. Coyle N, Adelhardt J, Foley KM, et al. Character of terminal illness in the advanced cancer patient: pain and other symptoms during the last four weeks of life. **J Pain Symptom Manage** **5**: 83-93, 1990.
18. Forbes K. Palliative care in patients with cancer of the head and neck. **Clin Otolaryngol Allied Sci** **22(2)**: 117-22, 1997.
19. Ethunandan M, Rennie A, Hoffman G, et al. Quality of dying in head and neck cancer patients: a retrospective analysis of potential indicators of care. **Oral Surg Oral Med Oral Pathol Oral Radiol Endod** **100(2)**: 147-52, 2005.
20. van den Beuken-van Everdingen MH, de Rijke JM, Kessels AG, et al. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. **Ann Oncol** **18(9)**: 1437-49, 2007.
21. Vecht CJ, Hoff AM, Kanssen PJ, et al. Types and causes of pain in cancer of the head and neck. **Cancer** **70(1)**: 178-84, 1992.
22. Porceddu SV, Rosser B, Burmeister BH, et al. Hypofractionated radiotherapy for the palliation of advanced head and neck cancer in patients unsuitable for curative treatment--"Hypo Trial". **Radiother Oncol** **85(3)**: 456-62, 2007.
23. Ong CK, Forbes D. Embracing Cicely Saunders's concept of total pain. **BMJ** **331**: 576-577, 2005.
24. Thompson E, Davies A. The last few days of life. Palliative care consultations in head and neck cancer. Chap 11. Oxford; 2006.
25. Markowitz AJ, Rabow MW. Palliative care for patients with head and neck cancer: "I would like a quick return to a normal lifestyle". **JAMA** **299(15)**: 1818-25, 2008.
26. Birkhaug EJ, Aarstad HJ, Aarstad AK, et al. Relation between mood, social support and the quality of life in patients with laryngectomies. **Eur Arch Otorhinolaryngol** **259(4)**: 197-204, 2002.
27. Babin E, Sigston E, Hitier M, et al. Quality of life in head and neck cancers patients: predictive factors, functional and psychosocial outcome. **Eur Arch Otorhinolaryngol** **265(3)**: 265-270, 2008.
28. Duffy SA, Ronis DL, Valenstein M, et al. Depressive symptoms, smoking, drinking, and quality of life among head and neck cancer patients. **Psychosomatics** **48(2)**: 142-148, 2007.
29. Ledebroer QC, Offerman MP, van der Velden LA, et al. Experience of palliative care for patients with head and neck cancer through the eyes of next of kin. **Head Neck** **30(4)**: 479-84, 2008.
30. Block SD. End-of-Life Care Consensus Panel. Assessing and managing depression in the terminally ill patient. **Ann Intern Med** **132(3)**: 209-218, 2000.
31. Laimer M, Kramer-Reinstadler K, Rauchenzauner M, et al. Effect of mirtazapine treatment on body composition and metabolism. **J Clin Psychiatry** **67(3)**: 421-424, 2006.
32. Vakharia KT, Ali MJ, Wang SJ. Quality-of-life impact of participation in a head and neck cancer support group. **Otolaryngol Head Neck Surg** **136(3)**: 405-410, 2007.
33. Clarke A, Cooper C. Psychosocial rehabilitation after disfiguring injury or disease: investigating the training needs of specialist nurses. **J Adv Nurs** **34(1)**: 18-26, 2001.
34. MacGregor FC. Facial disfigurement: problems and management of social interaction and implications for mental health. **Aesthetic Plastic Surgery** **14**: 249-257, 1990.
35. Partridge J. Changing faces: The challenge of facial disfigurement. Penguin, London; 1990.
36. Price B. A model for body-image care. **J Adv Nurs** **15(5)**: 585-93, 1990.
37. Mount B, Kearney M. Healing and palliative care:

charting our way forward. **Palliat Med** 17(8):  
657-8, 2003.

wounded: stories of soul pain, death and healing .  
New York: **Scribner**: 14, 1996.

38. Saunders C. Foreword. In Kearney M. Mortally

