



Nicholas Kalavrezos



Crispian Scully

Mouth Cancer for Clinicians

Part 13: Life After Mouth Cancer Treatment

Abstract: A MEDLINE search early in 2015 revealed more than 250,000 papers on head and neck cancer; over 100,000 on oral cancer; and over 60,000 on mouth cancer. Not all publications contain robust evidence. We endeavour to encapsulate the most important of the latest information and advances now employed in practice, in a form comprehensible to healthcare workers, patients and their carers. This series offers the primary care dental team, in particular, an overview of the aetiopathogenesis, prevention, diagnosis and multidisciplinary care of mouth cancer, the functional and psychosocial implications, and minimization of the impact on the quality of life of patient and family.

Clinical Relevance: This article offers the dental team an overview of prognostication, quality of life and oral and dental healthcare.
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The stage at which mouth cancer is diagnosed has a significant effect on overall survival and quality of life: early diagnosis reduces mortality and also minimizes:

- Morbidity and mortality;
- Disfigurement;
- Treatment duration;
- Costs.

Early diagnosis and treatment continue to be the target but, nevertheless, diagnosis is often delayed despite

exhortations over the past 25 years to increase the index of suspicion. The proportion of patients with head and neck cancer presenting with advanced disease has increased. Delays in diagnosis can lead to patients having more advanced stages of cancer, especially when delay is more than a month.

The quality of life (QoL) during and after mouth cancer treatment, however, has steadily improved over the years, despite survival rates increasing at a slower pace.

What factors influence cancer prognosis?

Localized mouth cancer confined to the primary site and small tumours (Stage I: <2 cm) have ~90% 2-year survival rate, but most cancers are found at a late stage, larger than 2 or even 4 cm (Stages III and IV), when survival is about one half as good. Indeed, about 60% of patients with mouth cancer present with late stage (Stages III and IV) disease. In general, prognosis decreases with advanced disease, low SES, advanced age and continuing risky lifestyles.

The most important prognostic factors are site and TNM (tumour, node, metastasis) stage. Guidelines for head and neck carcinomas from the Royal College of Pathologists state that other factors related to clinical outcome are grade, and pattern of invasion.

Several studies have reported that people with HPV-related mouth or oropharyngeal cancer have a better

How is cancer survival improving?

Survival rates for mouth and oropharyngeal cancers have risen slightly over the last 20 years. The best outcome for overall 5-year survival rates for treated oral cancers is over 90% for lip cancer. This relates presumably to the very early diagnosis at this site. The 5-year survival rates for treated cancers of the tongue, oral cavity, oropharynx are at best around 50–60%.

Nicholas Kalavrezos, FRCS, FFD RCSI, MD, Maxillofacial and Reconstructive Surgeon of The Head, Face and Neck, University College London Hospital and The Harley Street Clinic. Assistant Secretary, European Association of Cranio-Maxillofacial Surgery, (nkavrezos@icloud.com) and **Crispian Scully**, CBE, FMedSci, DSc, FDS, MD, Professor Emeritus, UCL, London, UK.

outlook than those who do not have HPV.

What factors may influence quality of life?

Treatment success is usually measured by the length of survival from cancer, which is the key primary endpoint and of major importance. Patients generally are living longer, but some continue to experience disease and treatment-related sequelae which can significantly affect the patient's 'quality of life' (QoL) (Figure 1: Articles 10, 11, 12) and impact not only on them but also their family, carers and others.

While the aims of cancer treatment must ideally be to remove/destroy the tumour entirely, the outcome in terms of QoL is a balance between positive results (survival) and adverse effects (sequelae). Oral cancer and its management are associated with tremendous physical, emotional and psychosocial disruption, as well as impaired functional status. QoL is a perceived subjective outcome which permeates many aspects of life to include well-being, life satisfaction and spiritual beliefs: the World Health Organization (WHO) defined QoL as 'individuals' perception of their position in life, in the context of their culture and value systems in their life in relation to their goals, expectations, standards and concern'. We all have individual coping styles and personality, so QoL as reported can differ hugely between patients at similar stages of cancer, treatment and recovery.

Health-related quality of life

Health-related quality of life (HRQoL) is a subset of QoL, involving:

- Physical functioning;
- Psychological functioning;
- Social interaction;
- Treatment-related symptoms.

A mouth cancer diagnosis, like any cancer diagnosis, is almost invariably accompanied by uncertainty, trepidation and fear, but head and neck cancer is often more emotionally traumatic than any other, since social interactions and emotional expressions and thus interpersonal communication depend, to a large extent of course, on the structural and functional integrity of the face and head and neck.

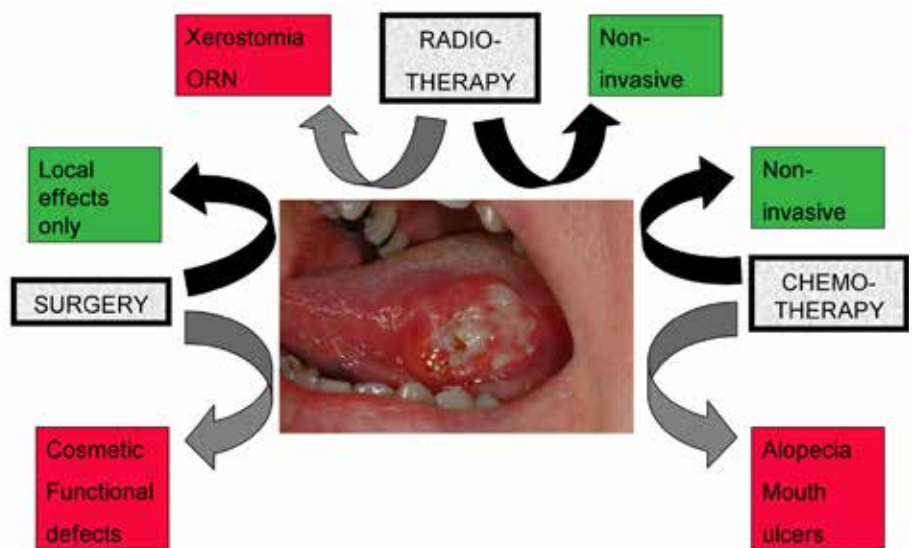


Figure 1. Mouth cancer treatments, advantages and possible sequelae (after Rogers and Scully 2010).

From the outset, most patients will be concerned of possible changes in appearance and may be aware that they almost certainly face some difficulties in eating, chewing, drinking, breathing, as well as speaking. Few of the patients can completely conceal the effects of treatment because of the obviously visible nature of their condition and treatment outcomes, especially obvious functional difficulties, and thus psychosocial dysfunction is almost invariably to be anticipated.

Socio-economic factors, cancer stage and culture can be especially important factors behind patient concerns. Patients of older age, lower annual family income, more advanced cancer stage and flap reconstruction tend to have significantly worse physical concerns, and those with lower annual family income, unemployment and more advanced cancer stage often report significantly worse mental health concerns.

HRQoL can be assessed by interviews or patient-completed questionnaires, sometimes available on computer systems, which can be used not only to record outcomes but also to inform the treatment decision, help change and shape clinical practice and for screening and intervention following treatment. Several validated questionnaires available include the Patients Concerns Inventory (PCI), University of Washington Quality of Life Questionnaire (UWQoLv4), the

European Organization for Research and Treatment for Cancer (EORTC QLQ H+N 35) and FACT H+N.

The main concerns include, alphabetically:

- Carer burden and support;
- Coping;
- Dental status;
- Disfigurement;
- Dry mouth;
- Emotional aspects;
- Feeding;
- Finance;
- Information;
- Intimacy;
- Recurrence;
- Rehabilitation;
- Shoulder movement;
- Speech;
- Swallowing;
- Trismus.

One study confirmed the *top ten* patient HRQoL concerns in mouth cancer as being as follows (starting from the greatest concern):

- Chewing;
- Speech;
- Swallowing;
- Saliva;
- Appearance;
- Activity;
- Pain;
- Taste;
- Shoulder;
- Mood.

Patients with oral cancer who have been diagnosed and treated early might have a better QoL. There is huge individual patient variation in perceived QoL, and patient expectations must be assessed and also carefully managed. Patients undergoing treatment for mouth cancer generally speaking have decreased QoL during and after treatment, especially in the first 3 months, irrespective of cancer stage or treatment used. Following treatment, QoL improves slowly in many people, but with lingering functional problems and psychosocial concerns, including fear of recurrence until, by 12 months post-treatment, matters usually stabilize. Some late effects of treatments persist beyond the end of treatment, especially aesthetics, xerostomia, swallowing problems and liability to osteoradionecrosis.

Patients with mouth cancer are more likely to be tobacco users and be alcohol drinkers and may have psychosocial difficulties which, with poor coping strategies, can lead to decreased levels of overall QoL. Nevertheless, most patients generally cope well despite their altered appearance and functional difficulties. Those patients that are at higher risk of experiencing poorer QoL and psychosocial dysfunction are usually those:

- With advanced disease;
- Requiring gastrostomy tube feeding;
- On combined treatment with multiple functional challenges;
- Unmarried or with poor social support;
- Younger patients.

HRQoL outcomes seem to be:

- More favourable after surgical treatment and tend to be maintained long-term;
- Worse after radiotherapy; mainly long-term due to post-radiation hyposalivation and trismus;
- Not good after chemotherapy or chemoradiotherapy, mainly because of mucositis and skin reactions in addition to any radiotherapy long-term adverse effects.

Factors impacting on QoL and often leading to psychosocial impacts are difficult to rank accurately in view of the individual variation, so they are dealt with here alphabetically.

Appearance

Disfigurement after treatment is most common after cancer surgery. Facial, oral and cervical swelling from post-operative inflammatory oedema and haematomas typically subside within weeks, but swelling resulting from lymphatic drainage disruption may take months to resolve. More permanent facial disfigurement can be seen, particularly if the resection also includes removal of bone, especially of the lower jaw, or large parts of facial skin or facial nerve involvement.

Facial disfigurement profoundly affects emotional well-being and social interactions and can easily lead to psychosocial issues such as:

- Anxiety;
- Depression;
- Interpersonal conflicts; and
- Social isolation.

Patients at greatest risk appear to be mainly females and those with poor social support.

Patients generally look to the reaction of partners, family and friends and from unwanted intrusions, such as staring and comments, to assess the effects of their disfigurement. Pre-operative expectation levels are also important.

Patients who cannot adjust well, and those exhibiting psychosocial difficulties, should be offered coping interventions, from encouraging the patient to engage early with self-care, to camouflage therapy, or referral to clinical psychology.

Dental health

Patients should have a dental assessment at the time of their cancer treatment planning. Dental and oral health must be maintained at a high level. Guidance concerning dietary intake and caries prevention is important, as is regular use of fluoride or Amorphous Calcium Phosphate (ACP) preparations, mouth-wetting agents (saliva substitutes) for those patients with a dry mouth, and care by the dental/oral hygienist.

Access for dental care can be an issue and it is important for a cancer patient to be able to have an urgent appointment, if required, and the dentition is important also for appearance, self esteem and psychosocial well-being. The dental status is critical in preventing osteoradionecrosis

(ORN). Teeth of dubious prognosis should be extracted before radiotherapy, since patients requiring extractions following radiotherapy are at risk of developing ORN.

Chewing is a key concern to patients after cancer treatment. Oral rehabilitation has an important role whatever the prognosis of the cancer, but needs to be in keeping with the patient's needs and motivation.

What are the main aspects of dental/oral management in patients with mouth cancer?

The oral health status in cancer patients may differ little from that of the general population but in some (especially in cancer high-risk groups) there may be poor oral hygiene, poorly maintained dentitions, periodontal disease, effects of tobacco/alcohol/betel use and ill-fitting prostheses. The main risk factors for oral complications of cancer therapy are pre-existent oral or dental disease and poor subsequent oral care. It is important to explain to cancer patients why they need to see the dental team, which is also the opportunity to educate about possible complications from cancer therapy, and patients' roles in maintaining oral health long-term.

Planning and timely oral health care before, during and after cancer therapy can reduce complications and assist with improving the QoL. The pressure to deliver prompt cancer treatment often forces dental clinicians to modify otherwise 'ideal' treatment plans. Satisfactory delivery of oral care can only be achieved if it is given due priority in patient care pathways and, in many circumstances, must be provided by the MDT specialist or the patient's primary care dental team, with advice from MDT.

After cancer treatment, bone augmentation is often used to replace or rebuild bone previously removed from the jaw during surgery. The 'gold standard' approaches for augmenting jaw bones involve using bone from other parts of the patient's body, however, the use of purified animal bone or using synthetically manufactured bone has also been attempted in small defects and when post-operative radiotherapy is unlikely. After jawbone restoration through reconstruction, osseointegrated

Procedures	Comments
ORTHODONTICS	Treatment can start once patient has been free of cancer for 1 year
Periodontal disease	Vigorous treatment is initiated, nonetheless causing minimal damage to adjacent structures; trauma can predispose to ORN
Restorations	Keep simple, ensuring acceptable aesthetics and function. Conventional glass ionomer restorations perform more poorly than resin-modified glass ionomer, composite resin and amalgam restorations in patients who have been treated with radiotherapy. Conservative restorative management of cavitated lesions is to be recommended in the first instance. Full/partial coverage crowns should be provided only when patient can demonstrate good oral hygiene. Should a full coverage restoration be warranted, the margins should be subgingival
Tooth extraction	If essential, perform with minimal trauma and, where possible, soft tissue primary closure. Although there is no conclusive evidence regarding pre-extraction antibiotic prophylaxis to prevent ORN, give prophylaxis and continued antibiotics until completion of healing: co-amoxiclav/amoxicillin (metronidazole in those allergic to penicillins). Where there is a high risk of ORN consider root canal therapy and restoration/crown amputation
Osseointegrated implants	A useful adjunct to fixed or removable prostheses. Routine use of zygomatic implants is not encouraged unless to facilitate the retention of an obturator. The placement of implants in patients treated with bisphosphonates is not recommended. Implant provision should take into consideration both the patient's prognosis and national guideline on their use
Appliance wearing	Dentures should be avoided unless necessary. Removable prostheses should be left out at night and subject to a cleansing regimen. Obturators should not be left out at night for 6 months following treatment. Obturators should be reviewed regularly. Appliance wear should be discontinued if mouth becomes painful

Table 1. Dental care of the mouth cancer patient. (Adapted from RCS/BSDH 2012.)

dental implants are used in combination with prostheses to restore the orofacial appearance and function. Intra-oral defects may require obturation to prevent deterioration of other dental structures and to facilitate the patient establishing social relationships. Maxillofacial prosthetic treatment may, in certain circumstances, be an alternative to reconstructive surgery, especially in patients who are not good candidates for surgery because of advanced age, poor medical condition which precludes long operative procedures, very large deformity, poor blood supply to irradiated tissue when anatomical parts are not replaceable by living tissue, when recurrence is likely, or when radiotherapy is being given. A temporary prosthesis may simply cover a defect when reconstructive surgery repair requires many steps, and speech appliances may be used when surgery is not applicable for a defect closure. Surgically reconstructed sites also may require prosthetic treatment with or without osseointegrated implants.

Maxillofacial prosthetic rehabilitation has advantages that it requires little or no additional surgery, can decrease a hospital stay, and often the results are more aesthetically pleasing and less invasive than some reconstructive surgery.

Patients often prefer to be treated at their own dentist for some procedures. Community dental teams may play a useful role. An off-site dental evaluation, where the dentist performs the entire evaluation and treatment planning guided by a protocol from the MDT could allow most treatment to be provided in the community, with the MDT specialist (restorative or special care) focusing on maxillofacial rehabilitation.

Detail on dental care advised is available in UK guidelines, *The Oral Management of Oncology Patients Requiring Radiotherapy, Chemotherapy and/or Bone Marrow Transplantation. Clinical Guidelines*. Updated 2012, The Royal College of Surgeons of England/The British Society for Disability and Oral Health.

(www.rcseng.ac.uk/fds/publications-clinical-guidelines/clinical_guidelines/documents/clinical-guidelines-for-the-oral-management-of-oncology-patients-requiring-radiotherapy-chemotherapy-and-or-bone-marrow-transplantation). This is the basis for Table 1.

Dental evaluation pre-cancer treatment

The primary aim is to eliminate or stabilize oral disease to minimize local and systemic infection. The teeth should be examined for periodontal disease, caries, failing restorations and loss of vitality. The fit, retention and stability of removable dental appliances should also be evaluated. The examination should include the neck lymph nodes, salivary glands, temporomandibular joint, masticatory muscles in addition to the mouth. Recent dental radiographs are essential. Patients may have limited ability to tolerate intra-



Figure 2. Maxillary and mandibular reconstruction on an edentulous patient following cancer treatment. Implant placement (courtesy of Dr Andrew Dawood).



Figure 3. Final implant retained prostheses (courtesy of Dr Andrew Dawood).

oral radiographs because of pain and limited opening, when a panoramic film is useful, with supplementary bitewings and selected periapicals if required.

Dental care before cancer therapy

The dental treatment plan is determined by the patient's individual wishes and circumstances. The management of a patient with a very poor cancer prognosis may be primarily symptomatic to improve comfort through removal of questionable teeth, dental prophylaxis and provision of simple restorations and removable dentures. Elimination of dental disease by judicious restorative dentistry and extraction of teeth with a questionable prognosis are important preventive strategies to avoid future dental extractions, an important risk factor for osteoradionecrosis (ORN). Teeth with doubtful prognosis (deep caries, deep periodontal pockets, non-vital teeth), or in direct association with the cancer, or in the direct path of the radiation beam should



Figure 4. Mandibular reconstruction with fibula flap after cancer surgery and implants inserted in the reconstructed jaw bone.

be extracted, ideally about 3 weeks before radiotherapy. Sharp edges of teeth or restorations should be removed to reduce the risk of trauma to the mucosa.

Preventive oral healthcare is important in reducing complications. Thorough plaque and calculus debridement should be achieved. Good oral hygiene should be established before radiation therapy begins. The main issue for dentate patients is the need to minimize caries by:

- Dietary advice to avoid caries;
- Preventive advice, maximizing tooth mineralization with fluorides and amorphous calcium phosphate before oral hygiene becomes difficult to maintain owing to mucositis and counter caries that arises from hyposalivation.

For most patients, complex treatment at this point is rarely indicated as there is insufficient time before cancer therapy begins.

Dental care during cancer therapy

Elective dental treatment should be avoided during radiotherapy: dental management is best limited to treatment of acute dental infections and symptoms. Patients may best discontinue wearing dentures during cancer therapy, to avoid soft tissue trauma. Oral mucositis, hyposalivation and infections must be managed, as below.

Dental care after cancer therapy

After surgery, patients will often

require rehabilitation to restore or improve their mastication, speech, swallowing and appearance. Osseointegrated dental implants placed in non-irradiated bone are often useful (Figures 2, 3, 4). Advances in CT and the use of stereolithographic models can help. The restorative dentist and clinical dental technician with specialist maxillofacial prosthodontic skills play crucial roles.

Dental implants in oral cancer patients are successfully used for dental rehabilitation after bony reconstruction of the jaws, and for retention of a prosthetic device (eg palatal obturator), used as the primary means of maxillary reconstruction. Combinations of microvascular surgical techniques and the use of implants can considerably improve the rehabilitation of people with severe head and neck defects, but there may be an increased risk of implant failure in irradiated free flap bone. It has been suggested that some patients may benefit from having the placement of implants during ablative tumour surgery. Reported implant success rates range from 40–100%.

Radiotherapy can significantly affect implant outcomes, mainly during the healing period, since it may induce endarteritis obliterans, and hence predispose to osteoradionecrosis (ORN). After previous radiotherapy a 5-year implant survival rate of up to 48% has been achieved, although bone within the 'primary field of radiotherapy' should be avoided for implant placement. Late complications may include bone loss and mucosal recession.

Several case-control studies have

- Avoid tobacco and alcohol
- Brush teeth gently after each meal. Use an ultrasoft, even-bristle TePe® brush and a bland toothpaste, preferably containing fluoride (eg Duraphat® 5000, BioXtra® toothpaste, Biotene® toothpaste). Brushing with a sodium bicarbonate – water paste is also helpful, Arm & Hammer® Dental Care toothpaste is bicarbonate-based and reduces the mouth's acid pH. If a toothbrush is too irritating, cotton Q-tip® swabs or foam sticks can provide some mechanical cleaning.
- Chlorhexidine has an antiplaque action and rinsing the mouth 2–3 times a day is helpful when you cannot follow other oral hygiene procedures. Rinses containing chlorhexidine can worsen established mucositis besides altering taste and staining teeth. Non-alcohol chlorhexidine rinses are best. Alternatively, rinse with a warm, dilute solution of sodium bicarbonate (baking soda) or salt and bicarbonate (warm water with 1/2 teaspoonful each of salt and baking soda) every two hours to bathe the tissues and control oral acidity. You can also cleanse the mouth with a pulsating water device, eg Waterpik® irrigators to remove loose debris.
- Apply fluoride gel to your teeth using custom applicator trays or by brushing the fluoride gel (or the Duraphat® 5000 toothpaste) onto the teeth for 5 minutes, after the usual toothbrushing. To ensure that the teeth are well coated with fluoride, the excess gel/toothpaste is spat out but the mouth not rinsed out. Patients showing signs of decalcification should also apply GC Tooth Mousse onto their teeth, to help remineralize them.
- Use a barrier forming mouthwash (eg Gelclair®, MugGard®) to reduce the discomfort from mucositis. Benzydamine hydrochloride (Difflam or Tantum) is a non-steroidal drug with anaesthetic, anti-inflammatory and antimicrobial properties which reduces discomfort from mucositis.
- A bland and soft lukewarm diet avoiding alcohol, caffeine or any other irritant such as tobacco products may help.
- Maintain hydration using a humidifier or vapourizer in the sleeping area to alleviate night-time oral dryness. If the mouth is dry, sip cool water frequently (every ten minutes). Allowing ice chips to melt in the mouth may be comforting.
- Mouth-wetting agents such as artificial saliva sprays, eg Xerotin®, Moi-Stir, Salivart, Xero-Lube, Saliva Orthana, can be used as frequently as needed. A mouth moisturizing gel like Biotene OralBalance® saliva replacement gel may be helpful. Keep the lips lubricated with petrolatum or a lanolin-containing lip preparation (eg BioXtra moisturising gel).
- Avoid commercial mouthrinses with alcohol, coffee, tea and colas with caffeine, as they tend to dry the mouth. Use alcohol-free mouthrinses with added fluoride (eg BioXtra® alcohol-free mouthrinse, Biotene® mouthwash).
- Sugarless lemon drops, eg Saliva Stimulating Tablets (SST®) help stimulate residual saliva gland activity.
- Sorbitol- or Xylitol-based chewing gum (eg BioXtra chewing gum) stimulate saliva flow and have an anti-caries effect.
- Medication like pilocarpine (Salagen®, 5mg tds) can also help increase saliva flow.

Table 2. Patient advice on oral care after mouth cancer treatment. (After Joshi V, Scully C. Cancer of the mouth for the dental team. Oral cancer: comprehending the condition, causes, controversies, control and consequences 18. Dental management. *Dent Update* 2012; **39**: 442–443).

shown improved outcomes in patients with a history of radiotherapy and implants with the addition of hyperbaric oxygen (HBO) therapy, mainly through reduction in the occurrence of osteoradionecrosis and failing implants. However, a systematic review found only one RCT comparing HBO with

no HBO for implant treatment in irradiated patients and was unable to find any strong evidence either to support or refute the use of HBO therapy for improving implant outcome.

To increase dental implant success in irradiated head and neck cancer

patients, the following precautions should be considered:

- Total radiation dose should be <66 Gy if the risks of ORN are to be minimized or <50 Gy to reduce osseointegration failure: avoiding implant site/portals;
- Hyperbaric oxygen should be given if >50 Gy radiation is used;
- Implant surgery is best carried out >21 days before radiotherapy or defer implant placement for 8 months;
- Plan implant placement away from the primary field of radiotherapy;
- Use implant-supported prostheses without any mucosal contact. Avoid immediate loading;
- No implant surgery should be carried out during radiotherapy;
- No implant surgery should be carried out during mucositis;
- Ensure strict asepsis;
- Consider antimicrobial prophylaxis.

Cancer chemotherapy appears not usually to impair the success of dental implants significantly. In a study of 30 post-surgical oral cancer patients receiving 106 dental mandibular implants plus adjuvant chemotherapy with either cisplatin or carboplatin plus 5-Fluorouracil, there was no significant difference in implant survival at 10 years follow-up when compared with matched controls. None of the patients had been treated with radiotherapy.

Regular follow-up visits are then important to:

- Identify early carious lesions with a view to avoidance of complex treatment or extractions Cervical and incisal 'radiation caries' can develop so advice is essential (Table 2), and compliance with diet, oral hygiene and fluoride use should be monitored;
- Identify early ORN or cancer recurrence so appropriate intervention can be provided.

Eating and swallowing

Eating and swallowing difficulties can follow cancer treatments. Eating requires additional time, which may reduce the pleasure. Oral malfunction can interfere with the types of foods and fluids that can best be chewed and swallowed. Oral incontinence may lead to avoidance of eating in public. Chewing and swallowing issues are common short-

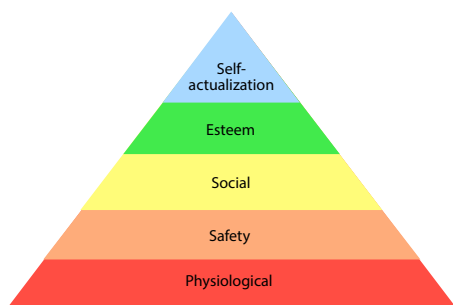


Figure 5. Maslow's triangle.

term after treatment; discomfort, hypo- or hyper-salivation, trismus and altered taste can impact, especially if there is mucositis, ulceration or dry mouth, or structural changes reducing tongue, jaw, pharyngeal or laryngeal movements from surgery and/or fibrosis from radiotherapy. Patients with severe dysphagia may require prolonged gastrostomy tube-feeding.

Patients with such issues may well benefit from referral to a dietitian and speech and language therapist.

Fatigue

Cancer and its treatment are often associated with fatigue, insomnia and sleep disturbance, and mood changes. The causes are unclear but may include the production of proteins by cancer cells, anaemia, depression and inadequate nutrition.

Strategies for management of fatigue include physical exercise, rest, massage, relaxation and psychotherapy.

Pain

Up to one-quarter of mouth cancer patients experience pain at 12 and 24 months after treatment. High levels of pain are associated with depression and a poorer QoL.

Analgesia needs may include opioids but, apart from constipation and other possible adverse effects, opioids may mask pulpitic symptoms and thereby hinder necessary dental interventions.

Psychosocial issues

A cancer diagnosis is often accompanied by fear and uncertainty, and any changes in appearance and dysfunction readily cause psychosocial issues in individuals with head and neck

cancer. Psychological morbidity is often underdiagnosed and emotional distress is often viewed synonymously with a cancer diagnosis. The prevalence of anxiety and depression are higher in head and neck cancers than for many other cancer diagnoses.

Depression is particularly high during cancer treatment and in the first six months following treatment, and mild to moderate depression may continue for three to six years after diagnosis.

Depression has been associated with patients who:

- Are younger;
- Have limited social support;
- Are unmarried or live alone;
- Have advanced cancer;
- Have multiple physical symptoms.

Ineffective coping strategies can be manifest as:

- Denial;
- Substance abuse; and
- Behavioural disengagement.

These are associated with anxiety and decreased QoL. Furthermore, the suicide rate in cancer patients is twice that observed in the general population, the risk being highest in the first 5 years after diagnosis.

Health and social care professionals should be able to recognize psychological distress and establish and maintain supportive relationships. Maslow's (1943, 1954) *Hierarchy of needs* can be adapted to cancer care as:

- Distressing symptoms, such as pain or dyspnoea;
- Fears for physical safety, of dying or abandonment;
- Affection, love and acceptance in the face of a devastating illness;
- Esteem, respect, and appreciation for the person;
- Self-actualization and transcendence (existence or experience beyond the normal or physical level) (Figure 5).

This could be used to provide an approach for patients' needs assessment, and the design of interventions to achieve aims that begin with comfort and potentially extend to the experience of transcendence.

The Clinical Nurse Specialist, Social Worker and Psychologist, in particular, focus on this area. Little is known about the effective management

of psychosocial dysfunction, but there is evidence that psychosocial interventions generally provide an overall positive effect, though education alone is inadequate. Patients prefer individualized Cognitive Behavioural Therapy (CBT), one-to-one therapy, followed closely by bibliotherapy, with group format being the least preferred option. Patients need and want written information: comprehensible information increases overall satisfaction, though many patient information leaflets are in language that is difficult for the public to understand. Written information is a cost-effective intervention that complements verbal advice.

Shoulder function

Patients who have had any form of neck dissection (Article 10) have worse QoL scores than those without.

Speech and voice

Speech is a concern for mouth cancer patients. Voice changes can be caused short-term by oedema and discomfort, and longer-term by the structural changes from surgery or fibrosis, mainly associated with radiotherapy. The psychological consequences can be profound. Patients must be well-informed about this and the techniques that aid voice rehabilitation before cancer treatment.

Xerostomia

Radiation-induced xerostomia is the most commonly reported late adverse effect of radiotherapy for mouth cancer. Lack of saliva (hyposalivation) affects speech, swallowing and perhaps taste, and can accelerate dental caries, candidosis and sialadenitis.

Strategies such as Intensity-Modulated Radio-Therapy (IMRT) can reduce irradiation of the parotid glands, which significantly reduces hyposalivation compared with conventional radiotherapy, and results in an improved QoL (Article 11).

What are the family issues?

Sometimes family members are the first to learn of a patient's cancer diagnosis. It is difficult to decide if they should or when they should tell the person affected. Although the family

may think that by not telling the patient they are protecting them, the person will probably sense something is wrong. A person with cancer may be resentful if they find out family members have kept the diagnosis secret. Most people can handle the news that they have cancer, but each person needs time to adjust and figure out what it means to them before they can be expressed and shared. During this time, friends and family members may be the targets of their loved one's strong, overwhelming feelings that need to be vented.

And even though family members and friends usually try to respond with love and friendship, it is natural for them to feel their own anger and frustration.

There may be things the cancer patient or family want or need to do, such as personal or legal matters. Even when a person with cancer has a good chance for a cure, they still need to discuss treatment options and goals, long-term treatment outcomes, and decisions about end-of-life care, including advance directives (living will and durable power of attorney for healthcare) with their doctors and their families. Friends and families may also have a hard time adjusting to the cancer diagnosis. They may have to cope with increased responsibilities while trying to manage many different emotions. On top of this, they want to try to be sensitive to the needs of the person with cancer.

The healthcare team have experience in such support and their input is often invaluable.

Changes in the family

A cancer diagnosis changes a family forever. Family and personal values are questioned and priorities are tested and changed. Unsettled feelings and arguments may resurface. Cancer can cause role changes; the household head may now be more dependent on other family members. Others may need to work outside the home or work different hours and, with new roles, interactions within the family can change. New responsibilities may overwhelm some. Parents might look to their children for support. If the children are old enough, they may be asked to take on more responsibilities within the household.

These requests often come at a time when the children themselves need support. Children might start acting younger and less mature in response to the stress. Teens, who are often rebelling and spending more time with friends, may instead cling to their families for support.

Although the person with cancer may not want to get outside help, friends and family members should look at their own limits and get any help needed. Certified Nursing Assistants, Home Health Aides, and other resources can help.

Relationships with others

It is not easy to talk about cancer, and patients may sense that some people feel awkward around them or avoid them. Cancer patients may also experience problems with sexuality following treatment, with younger patients experiencing more difficulties than older ones. Issues with sexual performance, reduced libido and enjoyment may be related to depression.

It is not unusual for people with cancer to withdraw, including from others, and their partners. It takes time for people with cancer to adjust to the way they feel about themselves and how they look.

Some people fear physical closeness to the patient because they wrongly believe they can catch cancer from their partner, or they are afraid they may hurt their partner.

Patients may find it easier and helpful to talk to a trained counsellor or psychologist, or to someone at a specialist helpline or at a local support group or an internet chatroom, such as:

- Cancer Research UK – *Cancer Chat*
- Macmillan Cancer Support – *Head and Neck Cancer Forum*

Disability issues

People with cancer are covered by the *Disability Discrimination Act*. Their employer is not allowed to discriminate because of the illness but has a duty to make 'reasonable adjustments' to help the patient cope. Examples include:

- Allowing time off for treatment and medical appointments;
- Allowing flexibility in working hours, the tasks to perform or the working environment.

The definition of what is 'reasonable' depends on the particular situation. The human resources department, union or staff association representative, or Citizens Advice Bureau should be able to advise.

Employment

Cancer presents a major potential financial burden. The complex treatment regimens can interfere with daily work patterns, not only for patients but also their families. After recovery, the debilitating and functional changes experienced can also restrict a cancer patient's ability to return to work in the same capacity or role.

Patients with cancers of the head and neck are amongst the cancer patients at highest risk for work-related disability or quitting work: up to one half the patients with mouth cancer are unable to return fully to work.

Patients may benefit from referral to a benefits adviser to ensure access to appropriate financial support. Patients or carers may be entitled to one of the following:

- *Statutory Sick Pay*: from the employer, if they have a job, but cannot work because of illness;
- *Employment and Support Allowance*: if they do not have a job and cannot work because of illness;
- *Carer's Allowance*: if caring for someone with cancer.
- *Other benefits*: if they have children living at home or if they have a low household income.

The Social Worker at the hospital can give the relevant information.

Free prescriptions

People being treated for cancer are entitled to apply for an exemption certificate, giving free prescriptions for all medication, including medicine for unrelated conditions. This certificate is applied for through the GP or cancer specialist and is valid for 5 years.

What about carers for people with mouth cancer?

Being a carer is not an easy role. A friend or family member helping to take care of the patient may also have

needs. Research on carers' health shows that high numbers of carers suffer health effects through caring, especially if trying to combine caring with a paid job or looking after a family. Both patients and care-givers need to know their limits and take rest when needed. Often families find themselves treating the person with cancer like an invalid, even when the person is fully capable of doing for him- or herself. They may need to at least try to do as much as they can on their own. These wishes should be respected if at all possible.

Carers Direct has useful information on its website www.nhs.uk/conditions/social-care-and-support-guide/Pages/what-is-social-care.aspx, and 0300 123 1053.

Further reading

1. www.clevelandclinicmeded.com/medicalpubs/diseasemanagement/hematology-oncology/head-and-neck-cancer/
2. www.cancer.org/treatment/treatmentsandsideeffects/emotionalsideeffects/copingwithcancerineverydaylife/a-message-of-hope-for-spouses-families-friends
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