Oesophageal cancer case based learning resource

Overview of the oesophageal cancer case study: Burt's story

This case study recounts the experience of Burt, a 68-year-old male diagnosed with oesophageal cancer.

The case study contains four sections:

1. Reduce risk.
2. Have the best treatment and support during active treatment.
3. Have the best treatment and support between and after active treatment.
4. Have the best care at the end of life.

It is recommended that you complete the sections and their related activities in order. This is because each section and each activity includes information that will help you complete the sections and activities that follow.

Learning activities

At times, you will have learning activities to complete. Click on the learning activities button and a list of questions will pop up. The questions will relate to the content you've just read or the video you've just watched.

Videos

There is a video component to this case study that is presented in 10 parts. You can watch the video clips when prompted throughout this case study or at any time by clicking on the video icon in the right-side menu. Learning activities throughout the case study will discuss the video and ask questions about it.

Resource links

Resource links are included throughout the case study. These links lead to interesting articles or websites, and are designed to encourage you to explore other available resources.

PDF of oesophageal cancer module
You can download a PDF version of the oesophageal cancer module.

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Aim of the oesophageal cancer case study

This case study aims to facilitate the development of competencies that reflect the role of the Specialist Cancer Nurse (SCN) in the delivery of evidence-based supportive care, including provision of information and education for people affected by oesophageal cancer.

Rationale

The person with oesophageal cancer is often required to undergo complex, multi-modal treatments. The disease and its associated management may result in a range of physical, psychological, spiritual and social changes, requiring a coordinated multidisciplinary approach to care.

Some facts about oesophageal cancer:

- Oesophageal cancer occurs three times more often in men.[5] This has been attributed to men's greater use of tobacco and alcohol.[6]
- In Australia in 2007, oesophageal cancer ranked 16th for incidence and 12th for mortality.[3]
- Between 1982 and 2007 there was a slight increase in the incidence and mortality from oesophageal cancer in Australia.[3]
- There was a significant increase in the male age-standardised mortality ratefor oesophageal cancer, with a 15% increase for the period 1983-2003. However by 2012 this trend appeared to be changing, with a 7% fall in age-standardised mortality rate for oesophageal cancer in men from 2003 to 2012.[7]

There are many points along the cancer journey when the SCN can improve outcomes for people at risk or affected by oesophageal cancer. These include:

Section 1: Reduce risk

- Possible risk factors for oesophageal cancer include a number of lifestyle behaviours which are amenable to change, including alcohol and tobacco intake. SCNs have an important role in public education to minimise these risks.

Section 2: Have the best treatment and support during active treatment

- People affected by oesophageal cancer require supportive interventions to deal with a range of physical, psychological, spiritual and social challenges when faced with this potentially life threatening disease and its associated multimodal treatments.

- Oesophageal cancer and the associated treatment effects impact individuals' quality of life. Within a multidisciplinary team, the SCN can support people affected by oesophageal cancer to make difficult treatment decisions, as they often have to weigh up survival and quality of life outcomes.

- Information provision is important in meeting the needs of people affected by oesophageal cancer.[8]

Section 3: Have the best treatment and support between and after active treatment

- The SCN, working closely with other members of the multidisciplinary team, supports people affected by oesophageal cancer to manage the impact of the disease and its treatment across all domains of health.

- Due to the nature of the disease and its short and longer term treatment effects, people affected by oesophageal cancer need support across the continuum of care, including when living in the community.

- The SCN collaborates with other care providers and facilitates supportive networks to ensure continuity of care and support.

Section 4: Have the best care at the end of life

- While radical surgery following neoadjuvant therapies has resulted in improved survival, late diagnosis means that curative treatments may not be available for many people diagnosed with oesophageal cancer. In these cases, palliative care can play an important role.

- The SCN plays an integral role in coordinating care and the range of services involved in providing supportive and palliative care.

- Supportive communication with people affected by oesophageal cancer may assist difficult decision making processes regarding treatment and supportive care interventions when a person's disease progresses.

Section 1: Reduce risk

Objectives

On completion of this section, you should be able to:

1. Interpret key epidemiological trends in the incidence and mortality for oesophageal cancer.
2. Explain current evidence regarding the risk factors associated with the development of different types of oesophageal cancer.

Oesophageal cancer in Australia

Oesophageal cancer is relatively uncommon. In 2011, it comprised 1.2% of all cancers in Australia.[5] However, the impact of this cancer is significant due to poor survival rates and its effects on an individual's quality of life.

In 2011, 991 men and 404 women were diagnosed with oesophageal cancer. The mean age at diagnosis in 2011 was 69.5 years in males and 74.8 in females. [5]

Five-year survival increased gradually between the periods 1982-1987 and 2007-2011, from 9.1% to 17.5%, but has not changed significantly since then.[5, 7] Five-year survival was similar for age groups under 70 (about 21%-23%), but dropped to 12% for those aged 70 and over.[3]

The most important independent predictor of survival is lymph node status. Five-year survival after potentially curative resection of locally advanced disease has been reported as between 20% - 37%.[6, 9]

Risk factors

Oesophageal cancers are histologically classified as squamous cell carcincoma (SCC) and adenocarcinoma.[4] Tobacco and alcohol are major risk factors for SCC and a moderate risk factor for adenocarcinoma. Risk of SCC decreases substantially after smoking cessation but remains unchanged even after several years of smoking cessation for adenocarcinoma.[4]

SCC is declining in incidence.[10] In contrast, adenocarcinoma of the distal oesophagus and the gastro-oesophageal junction, which is associated with Barrett's oesophagus, reflux disease and obesity, is rising steeply in the Western world, where it is now classed as the tumour with the fastest growing incidence.[9, 11]

Learning activities		
Completed	Activities	
☐	1	Examine the pathophysiology of gastro-oesophageal reflux and relate this to the development of oesophageal cancer.
☐	2	Discuss possible explanations for the increasing incidence of adenocarcinoma of the oesophagus.

Section 2: Have the best treatment and support during active treatment

Objectives

On completion of this section, you should be able to:

1. Explain the implications of dependence on alcohol and tobacco in planning and implementation of treatment and supportive care for people affected by oesophageal cancer.
2. Respond effectively to initial reactions and key concerns of people affected by a diagnosis of oesophageal cancer.
3. Discuss current treatment approaches for oesophageal cancer.
4. Analyse factors that might influence treatment decisions for the person with oesophageal cancer.
5. Use evidence-based approaches to facilitate the ability of the person affected by oesophageal cancer to participate in decisions about their treatment and care, according to their preferences.
6. Identify common potential and actual needs of people diagnosed with oesophageal cancer.
7. Implement supportive care interventions, including referral, to meet the multiple health needs of people affected by oesophageal cancer.

Experience of diagnosis

Symptoms associated with oesophageal cancer are described as insidious and progressive. This may explain the late presentation of symptoms and difficulties with diagnosis and management of the disease for general practitioners.

The predominant symptom, reported by 85%-95% of people with oesophageal cancer, is dysphagia (difficulty in swallowing). Dysphagia has physical, emotional and social ramifications that can impact on a person's quality of life.[12] At diagnosis, 30% of people with oesophageal cancer report pain.[13]

Diagnosis with oesophageal cancer is often unexpected and devastating to the person and their family. Specific issues can include:[14]

- existential concerns, particularly when the diagnosis is late
- a sense of guilt and responsibility for the diagnosis.

Nearly 50% of people with oesophagogastric cancer present with locally advanced or metastatic disease.[4, 15, 16] Newly diagnosed individuals are often faced with the challenge of an advanced stage, incurable cancer with a poor survival outcome.[4, 9,16] Supportive care screening and a comprehensive assessment of supportive care needs is required to ensure that the impacts of the disease, across all domains of health, are identified and taken into account when planning care. The SCN can reduce the difficulties experienced by people facing such decisions by providing information, education, and supportive care.

Following diagnosis, confirmed by biopsy, staging of oesophageal cancer generally involves physical examination, blood tests (including liver and renal function), endoscopy, and a CT scan.[17] Endoscopic ultrasound provides evidence of depth of tumour invasion, presence of abnormal or enlarged lymph nodes and occasionally evidence of lesions in surrounding organs.[4] When available, PET scans may help to locate otherwise undetected distant metastases. Laparoscopy may also be used to rule out peritoneal metastases.[17] The HER2 (Human Epidermal growth factor Receptor 2) status of the tumour can also be confirmed. The prognostic significance of HER2-neu expression is not clear. Overexpression seems to be associated with poorer survival, especially in individuals with SCC. [4]

Staging methods have improved to the extent that patients who have incurable disease can now be identified earlier.[11] Initial workup enables individuals to be classified into two groups with: [4]

- Locoregional cancer (stages I-III)
- Metastatic cancer (stage IV).

Learning activities	
Completed	Activities
☐	1 Access the NCCN Guideline – Esophageal and Esophagogastric Junction Cancers[4] (a free resource, but you must register and then click 'Remember me' to bypass the login page in future) and: • Review the TNM staging system for oesophageal cancer • Discuss reasons that oesophageal cancer is often diagnosed at a late stage.
☐	2 Compare the physical symptoms and psychological needs that may be common among people newly diagnosed with: • early stage oesophageal cancer

	• advanced oesophageal cancer.

Case Study: Meet Burt

Case study: meet Burt

Burt is a 68-year-old male recently diagnosed with oesophageal cancer.

Read Burt's health history, watch his first video, and then work through the learning activities. Use your notebook at the top of the screen to answer the learning activity questions and record your thoughts.

Burt's story 1: meet Burt

Health history

Patients name:	Burt Simpson
Sex:	M ☑ F ☐
Age:	68
History:	Presented to A&E ten days ago after a fall at the hostel in which he lives. A fellow resident rang an ambulance after Burt was having trouble getting up and appeared disorientated. Burt presented with >10kg weight loss in three months, malnourishment, dysphagia and pain associated with swallowing. Investigations have identified Stage III squamous cell carcinoma of the oesophagus. Staging has found loco-regional disease and no evidence of metastases. Co-morbidities include heavy alcohol and tobacco use, altered liver enzymes, and right-sided deafness. Burt appears to have limited social supports other than mates at the hostel. He is a retired labourer, currently on the pension.

Learning activities	
Completed	Activities
☐	1 Burt presents with tobacco and alcohol dependence. • Explain strategies a health care facility may implement to manage this dependence and ensure safety for Burt, other individuals and staff. • Discuss how other health team members may contribute to the multidisciplinary management of Burt.
☐	2 Review a supportive care screening tool used in your practice setting. • Evaluate how well this tool would assess Burt's needs. • Identify specific assessment data that may be needed to enable a more detailed assessment of Burt's social context.
☐	3 Examine factors that might impact on Burt's ability to effectively participate in education about his disease and its management.
☐	4 Discuss what Burt's immediate psychological needs may be.

Treatments and their impact

Core treatment options for oesophageal cancer include surgery, antineoplastic agents, and radiotherapy.

A summary of surgical interventions for oesophageal cancer and reported outcomes, principles, and approaches may be found within the NCCN Clinical Practice Guidelines in Oncology - Esophageal and Esophagogastric Junction Cancers.[4]

While surgery is the standard treatment for the majority of people with resectable oesophageal cancer, neoadjuvant combined chemoradiotherapy may also be used.[9, 19, 20] More than 50% of people affected by oesophageal cancer have unresectable tumours or metastases precluding them from curative approaches to treatment.[19]

Multiple modality treatment approaches incorporating combinations of surgery, radiotherapy and antineoplastic agents have been trialed with improved outcomes reported.[9, 16, 19, 21] Such approaches have been developed due to the risk of early systemic spread in oesophageal cancer and overall poor survival rates of people treated with resection alone.[16] In the recent CROSS phase III trial, it was concluded that preoperative chemoradiotherapy in individuals with eosophageal or junctional cancer improved locoregional control and was associated with an improved overall survival of 13%.[22]

Combinations of radiotherapy and antineoplastic agents are used as a curative treatment approach for localised non resectable squamous cell carcinoma, with survival outcomes equal to those for people who have curative surgery.[20] The major disadvantage of the combined treatment approach is the significant risk of acute toxicities.[21]

Radiotherapy and antineoplastic agents as single modalities have some limited use in advanced disease and palliation, yet there has been no associated survival advantage reported with their use. However, it may improve quality of life in people with symptomatic metastatic or unresectable oesophageal cancer through local disease control.[14, 23] Palliative radiation is usually well tolerated and can improve symptoms.[16]

In the future, biological and molecular targeted therapies may be more commonly used to treat oesophageal cancers.[24, 25] Many targeted therapies (like sunitinib and bevacizumab[24, 25]) are currently undergoing testing to assess their benefit and safety. Trastuzumab is a monoclonal antibody against HER2. Addition of trastuzumab to antineoplastic agents as a treatment for advanced HER2+ gastric or oesophagogastric junction cancers has been shown to increase overall survival when compared to chemotherapy alone.[26]

Resource link

Cancer Forum. November 2011

- Local therapies and resection in Barrett's Oesophagus and early oesophagogastric cancer
- Reviewing the role of cytotoxics in oesophagogastric cancer in the refractory, relapsed and advanced settings
- Australian perspective on the role of targeted therapies in gastroesophageal cancer
- Role of radiotherapy in operable oesophageal cancer

Learning activities	
Completed	Activities
☐	1. Review the NCCN Clinical Practice Guidelines in Oncology - Esophageal and Esophagogastric Junction Cancers[4] (a free resource, but you must register and then click 'Remember me' to bypass the login page in future). • Outline treatment options recommended for Stages I-II oesophageal cancer • Outline the current evidence based surgical approaches recommended in the management of oesophageal cancer.
☐	2. Develop a nursing care plan for pre and postoperative care for an individual admitted for an oesophagogastrectomy.

Treatment decisions

The SCN, as part of a multidisciplinary team, can provide supportive care and information to enable the person affected by oesophageal cancer to navigate their way through the complexities of their cancer journey. People affected by oesophageal cancer often face very difficult treatment decisions, weighing up survival against the quality of life impacts of treatments.

There is significant morbidity associated with surgery and other treatments for oesophageal cancer. Physical issues relate to food intake, fatigue, constipation and/or diarrhoea, and may impact even long-term survivors.[27]

Commonly reported psychological problems include depression and fears about metastases, physical suffering, and death.[27] Improving quality of life and enabling return to activities after curative oesophagectomy is achievable[28] and can be improved with targeted management and reduction of symptoms.[29]

Common quality-of-life issues associated with oesophageal cancer and its treatment regimens include:[6, 14]

- dysphagia and the inability to eat solid food
- fatigue
- guilt associated with a history of tobacco and alcohol use
- uncertainty
- end-of-life issues due to low survival rate.

The multimodal approach varies by clinical staging of oesophageal cancer. Factors which may be considered when developing a treatment plan include:[4, 19, 23, 30]

- location and size of lesion
- presence or absence of locoregional lymph nodes
- presence or absence of distant metastases
- cell type
- HER 2 status (adenocarcinoma of distal oesophagus or gastro-oesophageal junction)
- performance status
- individual's goals.

In addition, co-morbidities can influence the specific detail of the treatment plan and selection of the particular chemotherapeutic agents.

Learning activity	
Completed	Activity
☐	1 Examine the factors that may influence treatment planning for oesophageal cancer and, for each factor, explain how this would be assessed. • Where treatment options are not definitive, explain the factors that a multidisciplinary team might consider in recommending a treatment plan.

Case study

Burt's story 2: Treatment decisions

Learning activities		
Completed		Activities
☐	2	A multidisciplinary team meeting is planned to discuss Burt's case. • Justify the role of a multidisciplinary team meeting in Burt's case. • List the health professionals who would participate in such a meeting. • Explain the key contributions that each health professional would make to develop a plan for Burt's treatment and supportive care. Use a supportive care screening tool used in your practice setting when considering your response.
☐	3	Plan in detail how you would support Burt in the process of making treatment decisions.
☐	4.	How would you respond to Burt's question about why he is not eligible for surgery? In your response, outline the indications and contraindications of surgical therapy for oesophageal cancer.
☐	5	Burt is beginning to open up about his family and concerns for the future. Formulate strategies to support Burt in dealing with existential issues at this point in his cancer journey.

Treatment plan

After reviewing the evidence and Burt's circumstances, the multidisciplinary team has recommended the following treatment plan for Burt:

Treatment plan	
Patients name:	Burt Simpson
Sex:	M ☑ F ☐
Age:	68
Plan:	Chemoradiation
	Week 1: 4 days continuous 5FU 1000mg/m^2/day / Day 5 Carboplatin AUC5 via a peripherally inserted central catheter (PICC)
	5 weeks XRT
	Week 5, 8 &11: 4 days continuous 5FU 1000mg/m^2/day / Day 5 Carboplatin AUC5 via a PICC
	AUC5 (Area Under the Concentration x Time curve)
	The multidisciplinary team has recommended that Burt have the initial phase of his treatment as an inpatient, then the remainder as an outpatient.

Learning activities		
Completed		Activities
☐	1	Access the eviQ Cancer Treatments Online: • Outline the recommended treatment regimen for Burt's Stage III squamous cell carcinoma of the oesophagus.
☐	2	Burt's treatment protocol is modified from the recommended guidelines. Discuss the factors in Burt's case which may have been considered in modification of the treatment protocol.
☐	3	Following the multidisciplinary team meeting, you meet with the bed manager who has questioned why Burt is to remain an inpatient during the initial phase of treatment. Evaluate whether inpatient management for Burt is justifiable.
☐	4	Examine the common quality of life concerns that are likely to be associated with Burt's proposed treatment plan.

Case study	
Burt's story 3: Treatment plan	

Learning activities		
Completed	Activities	
☐	5	Debate the extent to which you believe Burt's preferences and goals have been considered in this case.
☐	6	Design and role-play an education session on insertion and management of his PICC.
☐	7	Design a care plan for managing Burt's dysphagia and odynophagia that incorporates best available evidence.
☐	8	Examine the common side effects of a treatment regimen such as Burt's.
☐	9	Design an education plan for Burt regarding the planned treatment regimen and its effects. Include discussion of the content and delivery approaches.
☐	10	Analyse how Burt's dependence on alcohol might be taken into account in planning and delivering his care.

Supportive care

Much of the treatment for oesophageal cancer is provided on an outpatient basis. A range of social and community supports are critical for the ongoing support of people while undergoing treatment for oesophageal cancer.

Family members and carers are a key component of this support. These family members will also often experience significant fear, anxiety, feelings of uncertainty and hopelessness as a result of the challenges associated with treatment for oesophageal cancer.[14]

Family members also require support and information to deal with the uncertainty and sequelae of oesophageal cancer and its management.[14, 31]

Case study

Burt's daughter Jenny visits him in hospital.

Burt's story 4: during treatment

Learning activities		
Completed		Activities
☐	1	Burt indicated that he would use Meals on Wheels. Explore the services available in your local area to meet the needs of people like Burt and identify: • the extent these services are able to meet the needs of individuals requiring special meals • the process for referral to such services • the likely costs of such services to the individual and/or the referring health care service.
☐	2	Design a plan for how you would assess the needs of family and carers of a person with oesophageal cancer.
☐	3	Reflect on circumstances in Burt's case and/or your own clinical experiences when there has been family conflict. Identify strategies that may be used to effectively manage these circumstances.
☐	4	Formulate strategies you would use as an SCN to support Jenny at this point in Burt's cancer journey.

Section 3: Have the best treatment and support between and after active treatment

Objectives

On completion of this section, you should be able to:

1. Examine the supportive care needs of people affected by oesophageal cancer between and after active treatment.
2. Implement evidence-based clinical and supportive care nursing interventions for the person between and after active treatment for oesophageal cancer.
3. Appraise nutritional support interventions for the person following treatment for oesophageal cancer.
4. Collaborate with other care providers to ensure a coordinated, planned and documented approach to meeting supportive care needs for the person following initial treatment for oesophageal cancer.
5. Make appropriate and timely referrals for psychological care and support for the person with oesophageal cancer.
6. Analyse factors which may influence a person's adherence to recommended health care interventions following treatment for oesophageal cancer.

After treatment

While the treatments for oesophageal cancer may result in improvements in symptoms experienced by people with this cancer, many people will continue to have ongoing and complex supportive care needs. Symptoms which may impact on the quality of life of people affected by unresectable or locally advanced oesophageal cancer include dysphagia, pain, bleeding and nausea and vomiting.[16]

Key issues for people with oesophageal cancer are commonly nutritional compromise and social and community support.

A clear plan, developed with and agreed upon by the individual, needs to be established to avoid excessive follow up by multiple specialists,[32] and to meet the complex needs of people affected by oesophageal cancer.

The general practitioner has a key role in follow up of individuals in the community.[32]

Ongoing monitoring following treatment will include evidence of progression of the disease and the need for further medical intervention to control or palliate the disease should there be a recurrence.

Learning activities		
Completed	Activities	
☐	1	Discuss the new and ongoing physical, psychological, spiritual and social support needs that may be commonly experienced by people following initial treatment for oesophageal cancer.
☐	2	Explain the ongoing clinical assessment that would be required to monitor the person for disease progression following initial treatment for oesophageal cancer.

Social and community supports

Following completion of treatment, a range of social and community supports can be used to ensure the needs of people affected by oesophageal cancer are met.

Individuals have reported that exchanging experiences with other people affected by cancer provides an understanding about the illness and the future.[8]

An example of a peer support group for people with oesophageal cancer is the UK-based Oesophageal Patients Association.[33] The objectives of the group are:

- to help new patients and their families to cope with any difficulties arising as a result of treatments for oesophageal/gastric conditions (predominantly cancers)
- to give support and encouragement towards a good quality of life.

Each of the state Cancer Councils in Australia has a local Cancer Connect service. Cancer Connect is a telephone-based peer support program where people affected by cancer receive one-on-one support from a cancer survivor, matched according to cancer type, treatment, age and family circumstances.[34]

Learning activities		
Completed		Activities
☐	1	Identify local networks and resources to support people affected by oesophageal cancer. An example is the Stomach and oesophageal cancer booklet[35] by the Cancer Council New South Wales.
☐	2	Analyse relevant literature to outline the potential benefits and risks of peer support, and the evidence about the characteristics of effective peer support.
☐	3	Explain how the SCN can facilitate peer support.

Case study

Burt's story 5: social and community supports

Learning activities		
Completed	Activities	
☐	4	Explain the key components of an effective discharge planning process to ensure Burt's discharge needs are identified and the safety of his home environment is ensured.
☐	5	Analyse the factors that might have contributed to Burt's non-adherence to recommended treatments.
☐	6	Formulate interventions that can be implemented to encourage Burt's adherence to his recommended post-treatment care plan.
☐	7	Explain why the palliative care service has been asked to consult at this stage of Burt's cancer journey.
☐	8	Appraise strategies the SCN could use to promote continuity of Burt's follow up care between multiple health service providers that may be involved.

Nutritional issues

Malnutrition in the person with oesophageal cancer may be caused by the tumour location, pre-morbid lifestyle, or treatment side effects. The impact of these factors on functional swallowing and nutritional status may be acute and/or chronic.[36]

Nutritional assessment for the person with oesophageal cancer is required to:[37, 38]

- confirm the presence, extent, degree of severity and type of malnutrition
- determine the nutritional needs of the person and the nutritional support required
- provide the basis of the treatment plan and monitor the progress of those receiving nutritional support
- determine whether their nutritional needs are being met.

Nutritional assessment involves a person's history, physical examination, anthropometry, and biochemical assessment. Validated nutrition assessment tools (e.g. scored Patient Generated-Subjective Global Assessment (PG-SGA) or Subjective Global Assessment (SGA)) should be used to assess the nutritional status of people receiving radiation therapy.[39]

Dysphagia is a common symptom in advanced oesophageal cancer and may impact on an individuals' nutritional status. Dysphagia may also impact all domains of a person's health, resulting in:[40]

- increased susceptibility to infections (stomatitis)
- communication difficulties
- dry mouth
- halitosis
- drooling
- choking
- low self-esteem and isolation.

The goal of management of dysphagia is palliation of symptoms and increased quality of life. In conjunction with other nutrition interventions, restoration of swallow may be achieved via the following options:[16, 41]

- endoscopic lumen restoration or enhancement
- placement of permanent or temporary self-expanding metal stents
- external beam radiotherapy
- brachytherapy
- antineoplastic agents
- laser therapy
- photodynamic therapy
- ablation using an injection of alcohol or chemotherapeutic agent.

None of these interventions has been shown to necessarily be superior to another. Interventions need to be chosen to meet the person's individual requirements.[41] A multimodality multidisciplinary approach is encouraged.[16]

Radiation therapy can also have significant impact on the nutritional status of people undergoing treatment. Interventions to address nutritional needs of individuals receiving radiation therapy have been associated with:[39]

- reduced treatment breaks
- reduced unplanned hospital admissions
- decreased costs compared with usual care
- improved outcomes (quality of life, physical function and satisfaction).

Individuals with oesophageal cancer who receive chemoradiation are at high risk of malnutrition. This can exacerbate the effects of treatment.[42] Current evidence-based guidelines recommend that all individuals receiving radiation therapy to the gastrointestinal tract or head and neck area should be referred to a dietitian (and/or other nutrition support).[39] Nutritional intervention can improve the recovery of functional capacity for people with oesophageal cancer after radiotherapy, and improve their postoperative outcome after surgery.[38]

The goals of nutrition intervention in people receiving radiation therapy are to minimise weight loss and maintain quality of life and symptom management. Current guidelines[39] recommend that:

- Dietary counselling and/or supplements are effective methods of nutrition intervention, along with frequent (at least fortnightly) dietitian contact to improve outcomes in people receiving radiation therapy.
- People receiving radiation therapy to the oesophagus should be referred prior to commencement of treatment for consideration of prophylactic gastrostomy/jejunostomy.
- People affected by oesophageal cancer presenting with severe nutrition risk factors (severe dysphagia, and/or body mass index < 18kg/m2, and/or unintentional weight loss > 10%) are likely to require tube feeding.
- Both nasogastric tube (NGT) and percutaneous endoscopic gastrostomy (PEG) tube feeding are effective nutrition interventions and the method of feeding depends on anticipated length of therapy.

Decisions about nutritional interventions need to take into account the person's preference and prognosis.

SCNs play a critical role in identifying the person's goals and preferences, assisting them to ensure these are considered in nutrition care planning. SCNs can also play an important role as advocates in ensuring the person's wishes are incorporated into care planning.

Resource link

Cancer Forum. November 2011

Nutritional status and fitness in neoadjuvant chemoradiation for oesophagogastric cancer[38]

Learning activities	
Completed	Activities
☐	1 Analyse the factors that may contribute to nutritional compromise in the person with oesophageal cancer.
☐	2 Access the Evidence based practice guidelines for the nutritional management of adult patients with head and neck cancer,[43] and: • summarise recommendations for nutritional screening and assessment • outline the implications of these recommendations for the SCN.
☐	3 Access the Evidence based practice guidelines for the nutritional management of patients receiving radiation therapy.[39] Explain the following interventions and their role in managing nutritional problems for people with oesophageal cancer: • nutritional supplements • PEG • nasogastric feeding • stenting • pharmacological interventions.
☐	4 Examine factors that are considered when deciding on nutritional interventions for people with oesophageal cancer.

Case study:

Burt's nutritional status is becoming further compromised. He attends a meeting with the medical oncologist to discuss options, and decides to have a PEG tube.

Burt's story 6: nutritional issues

Learning activities		
Completed	Activities	
☐	5	Formulate strategies that you would use to ensure Burt's preferences and goals were considered in making decisions about ways to address his nutritional needs.
☐	6	Review current evidence that you would use to inform decisions about whether medically administered nutrition and hydration would be warranted for Burt.
☐	7	Burt will be discharged home to his hostel with PEG tube feeds in situ. As the SCN planning his discharge, explain how you would arrange necessary community supports for him to administer his feeds at home.
☐	8	Design an education plan to assist Burt with management of his PEG tube at home.
☐	9	Discuss how you would respond to a question about administration of alcohol via the PEG tube.

Section 4: Have the best care at the end of life

Objectives

On completion of this section, you should be able to:

1. Analyse an SCN's role in facilitating the transition to palliative care for people affected by oesophageal cancer.
2. Demonstrate effective communication skills in discussing end of life concerns with people affected by oesophageal cancer.
3. Facilitate collaborative decision making between people affected by oesophageal cancer and health care professionals about end of life care.
4. Analyse the supportive care needs of people with advanced oesophageal cancer and their family and carers.
5. Implement interventions that are consistent with an individual's preferences and abilities to optimise their functional abilities at end of life.
6. Identify the signs of impending death and explain such information to family and carers.
7. Identify specific risk factors for complicated bereavement in family and carers and demonstrate appropriate support and referral.

Transition to palliative care

Palliative care, including bereavement support, is often required for people affected by advanced oesophageal cancer. The transition from curative to palliative care requires sensitive management involving open communication between people affected by cancer and all multidisciplinary team members, including SCNs. Effective communication between health care providers and people affected by advanced cancer is essential to providing optimal palliative care.[44] Family meetings can facilitate effective communication and provide opportunities for sharing information, discussing goals of care, and future planning with people affected by cancer.[44]

Living with uncertainty is identified as an especially difficult challenge for people with advanced oesophageal cancer. The following points have been compiled to assist clinicians if asked for a precise prognosis: [45]

- explore the reasons behind the request – people know the provider cannot be certain
- acknowledge the difficulty of living with uncertainty
- review plans that are based on knowing a definite prognosis
- provide information when requested – this helps restore a sense of control and allows realistic planning
- reassure the person that this state of illness will not be endless
- leave a broad framework for prognosis (e.g. weeks to months, days to weeks).

Accurately communicating where a person is on their cancer illness trajectory to the person and other care providers can be difficult. Such communication is especially difficult when multiple care providers are involved in the provision of care for a person with complex care needs.

Effective communication facilitates collaborative decision making between people affected by cancer and the MDT.[44] The needs and wishes of the person affected by cancer and their caregivers and family must be respected when care planning; this is a cornerstone of providing optimal care, according to the Standards for providing quality palliative care for all Australians.[5]

Learning activities	
Completed	Activities
☐	1 Summarise factors that would facilitate or hinder the transition to palliative care for a person with advanced oesophageal cancer. Considering these factors, discuss the role of the SCN in supporting the transition to palliative care.
☐	3 Access the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer[8], and: • Review the 'Recommended steps for preparing people for transition to palliative care' on page 63 of the guidelines. Critique current practice in your health care facility in light of these recommendations. • Review the 'Recommended steps for discussing prognosis with individuals with cancer' on page 50 of the guidelines, and: ○ reflect on your capabilities in applying these steps ○ identify strategies for improving your skills in applying these steps.
☐	4 Access Family meetings in palliative care: Multidisciplinary clinical practice guidelines[44], and: • Design a strategy for how you, as an SCN, would implement or improve the use of these guidelines to facilitate collaborative decision making between health care professionals and people affected by oesophageal cancer.

Case study:

Burt's story 7: transition to palliative care

Learning activities		
Completed	Activities	
☐	5	Reflect on how you would answer Burt's question about his prognosis, and how you feel about such conversations.
☐	6	Burt used the term 'kick the bucket' to refer to his time of death. Explain how culture may influence the language we use as we communicate such information.
☐	7	Role-play your response to Burt's question and evaluate your response using the recommended steps for discussing prognosis with individuals with cancer on page 50 of the Clinical Practice Guidelines for the psychosocial care of adults with cancer.[8]
☐	8	Explain how you will communicate Burt's prognosis and other relevant information to other members of the multidisciplinary team.

Optimising function in palliative care

One of the key goals of palliative care is to optimise a person's quality of life. For many people, this will include optimising their ability to engage in day to day activities, including self-management of their health problems.

The extent to which people wish to self-manage their health needs will vary, and is likely to change over time. The SCN has an important role in determining goals and preferences of people with progressive disease, and in designing an approach to care that respects these desires. The SCN also requires skills in supporting people when their wishes may not be able to be met, due to declining abilities or personal resources.

Families and carers also play an important role in enabling people to maintain their day to day functioning. The SCN needs to assess the person's family and social situation to identify their supportive care needs.[45] Planning to support the person requires consideration of family and carer resources, as well as other community and social supports.

Learning activities		
Completed	Activities	
☐	1	Explain nursing interventions that the SCN may implement to optimise a person's functional ability as disease progresses.
☐	2	Compare and contrast the meaning of self-management at different phases of the cancer journey.
☐	3	Formulate strategies the SCN can use to understand a person's goals, preferences and abilities to manage their health problems as their disease progresses.

Case study:
Burt's story 8: optimising function 

Learning activities		
Completed	Activities	
☐	4	The SCN explains that Burt appears to be managing his self-care needs at this time. Outline the nursing assessment you would undertake to confirm this.
☐	5	Explain nursing interventions that may contribute to Burt's ability to manage at home effectively.
☐	6	Explain how you would respond to Burt's daughter Jenny's question about his use of alcohol at this time.
☐	7	Jenny seems to be looking for ways to become closer to her father. Describe how you would enable Jenny to become more involved in her father's care.
☐	8	Identify other health professionals and community services that would be engaged to support Burt and Jenny at this stage of his cancer journey.

Common supportive care needs during the palliative phase

Some common supportive care needs for the person undergoing treatment for oesophageal cancer relate to the following areas:

- Nutrition and hydration
- Choice of place of care
- Financial concerns

Nutrition and hydration

As discussed in the previous section, individuals with oesophageal cancer who are undergoing treatment are at high risk of malnutrition and its complications.[42]

Support in the form of consultation with a dietician is recommended for individuals in the palliative phase.[47] Some common dietary interventions for people experiencing dysphagia include encouraging them to have small, frequent meals that are high in energy and protein, and encouraging them to consume nourishing drinks that are the right consistency.[48]

Nutritional care in the final weeks of life typically includes the treatment of dry mouth and thirst, along with family and carer education and support to deal with the psychological aspects of discontinuing feeding.[47]

Resource links

- Artificial Nutrition, 2010. CareSearch

Choice of place of care

The Standards for providing quality palliative care for all Australians[46] emphasise the importance of decision-making and care planning that takes into account the unique situation of each person transitioning to palliative care, their caregivers, and friends. Care and support should be coordinated to minimise the burden on these groups.[46]

A comprehensive palliative care assessment should be carried out when the person with cancer transitions to palliative care. This assessment should take into account the person's goals and expectations in relation to place of care.[47]

Health care professionals should discuss the dying person's prognosis with them in a manner that is clear and consistent.[47] This helps to allow the person and their family to develop realistic expectations about the process of dying and setting goals about the place of their death,[47] and enables SCNs to plan for ongoing care and support needs.[46]

The role of the primary caregiver is often rewarding, but can also be very stressful.[46] The caregiver can have different preferences to the person who is dying, in regards to place of care. The SCN should assess the needs of the primary caregiver/s independently, and plan appropriate supportive strategies.[46] A bereavement assessment, conducted prior to death, can indicate want kind of support a carer will need after the death of their loved one.[49]

Learning activity	
Completed	Activity
☐	1 Access Module Four of the PCC4U website[50]. Read the content of Activity three, on establishing goals of care, and complete the thinking points linked to this activity: • Discuss how you would describe the primary goals of palliative care. • Describe how you can assess a person's preference for their care. • What are some of the reasons that individuals with life-limiting illnesses may continue to have the goal of cure? • How would you, as a health care professional, respond to the following situations: a) the person's goals may not be consistent with their prognosis b) the care goals conflict with the goals and wishes of their family. • In what ways might beliefs and culture influence personal goals and preferences for care? (used with permission from the PCC4U website[50])

Financial concerns

People undergoing treatment for cancer may have many concerns about financial issues.[8] Financial concerns can include the cost of extra nutritional support and medications, as well as travel to and from hospital for treatment. Other financial concerns for people with cancer may also include the cost of: [8]

- accommodation
- supportive treatments like seeing a counsellor or psychologist
- childcare
- prostheses
- wigs
- continence aids.

Many people from rural and remote areas may need to travel a long distance to receive treatment, and this may result in substantial financial burdens.[8]

Many health services have social workers who are available to provide advice on where to seek financial assistance.

Resource links

People receiving treatment for cancer may be unaware of the financial assistance available to them.[8] Access the following sites for further information on financial assistance:

- Centrelink has a range of payments that may be paid for people living with illness, injury or disability. They also have a range financial assistance and services for those caring for someone with an illness or disability.
- Some states subsidise the cost of travel for people who are required to travel over 100km to receive specialist medical treatment. For instance, South Australia has the Patient Assistance Transport Scheme (PATS) and Queensland has the Patient Travel Subsidy Scheme (PTSS).
- The Cancer Voices SA website has information on financial issues.
- Veterans and war widows who develop cancer may receive financial assistance from the Department of Veterans Affairs for services, equipment and medications.
- Some state-based cancer organisations provide limited financial assistance; their contact details can be accessed via the Cancer Council Australia website.

Learning activities	
Completed	Activities
☐	1 Identify the individual/s or support services you could refer to regarding financial requirements.
☐	2 Investigate whether your state or territory has a travel subsidy scheme. If it does, what are the eligibility requirements?

When death is imminent

It can be difficult to differentiate a decline in health due to an acute reversible problem, from the natural progression of a life-limiting illness towards death.[51]

Changes that alert to a predictable death include:[51]

- decreasing mobility
- decreasing interest in food and fluid
- increasing periods of introspection
- more time spent sleeping
- continued global changes in weight and energy levels.

There are a range of pharmacological and non-pharmacological interventions that are critical to maximise comfort at this time.

For the family, there are a number of important issues for the SCN to consider prior to the person's death:[52]

- Would a family meeting be beneficial?
    - Family meetings at this point in the cancer journey provide opportunities to:
        - ask questions
        - express fears and concerns
        - identify areas of conflict
        - provide opportunities for sharing grief between family members
        - identify whether family members are engaging in protective behaviour by not talking about the death.
- Is the family prepared for the individual's death?
- Does the family want to be present at the time of death?
- Does the family understand what they see happening to the individual – are the physical signs of disease progression or dying recognised?
- Is there unfinished business between the individual and the family?

Learning activities		
Completed	Activities	
☐	1	Reflect on your experience of caring for people who are dying, and: • describe the changes you've observed to indicate imminent death • explain the pathophysiology of the changes.
☐	2	Compare the similarities and differences of a family meeting at initial transition to palliative care, and when the person is imminently dying.
☐	3	Discuss specific strategies for involving family and carers in decision making and care as death becomes imminent.

Case study:
Burt's story 9: when death is imminent 

Learning activities		
Completed	Activities	
☐	4	Formulate nursing interventions for Burt to respond to the following concerns: • noisy breathing • changing levels of consciousness • mouth and skin care.
☐	5	Examine the role of the following pharmacological agents in dealing with Burt's symptoms at this time, and the nursing implications associated with administering: • analgesics • anticholinergics.
☐	6	Evaluate Brad's response to Jenny, and identify strategies for improving support for Jenny at this time.

Grief and bereavement

A family-centered approach that acknowledges the possibility of grief in all family members is part of palliative care.[51] SCN interventions to minimise grief can be implemented early to reduce the risk of complicated bereavement reactions or longer term psychological distress.

Supportive interventions, both before and after bereavement, need to be tailored to the individual needs of the person. Around 10-20% of bereaved people experience complicated bereavement, which has many symptoms.[53] While symptoms such as severe depression or suicidal thoughts are more obvious, other symptoms may go unnoticed and undiagnosed. Completing a bereavement risk assessment is important to early intervention.

Resource links

Websites:

- Grieflink[54]
- CareSearch[55]
    - End-of-life care
    - Bereavement, Grief and Loss

Learning activities		
Completed	Activities	
☐	1	Distinguish between a normal bereavement reaction and a complicated bereavement reaction.
☐	2	Identify risk factors for a complicated bereavement reaction.
☐	3	Review the CareSearch[55] website and identify tools used to assess bereavement risk factors. Discuss where, when, and who should use such tools to identify risks.
☐	4	Discuss how your practice setting may implement policies and practices to minimise grief experienced by families and carers at end of life. Consider issues such as visiting hours, overnight stays, transport and parking.

Case study

Burt's story 10: complicated bereavement

Learning activities	
Completed	Activities
☐	5 Utilise one of the Bereavement Risk Assessment Tools from CareSearch[56] to determine Jenny's risk of a complicated bereavement reaction.
☐	6 Discuss how you would involve other members of the health care team in assessing Jenny's need for bereavement support.

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