Module 1: Workbook

Principles of palliative care

To provide healthcare that is relevant to community needs, you need to understand the experiences, preferences and care requirements of people affected by life-limiting illness.

Overview

Module 1: Principles of palliative care will help you develop the knowledge and skills needed to provide quality care to people affected by life-limiting illness (which includes those people with a life-limiting illness, their families and carers). Through personal reflection you will also examine how your own values and beliefs about dying and death affect your responses and interactions with people affected by life-limiting illness.

Aims and objectives

You'll develop an understanding of the social and personal experiences of people with life-limiting illnesses and their families. This module will also cover the core principles of palliative care.

After completing this module you should be able to:

- Analyse the factors that influence contemporary community perceptions about dying, death and bereavement
- Recognise how your personal values and beliefs about dying and death influence your responses and interactions with people affected by life-limiting illness
- Describe the core principles of palliative care
- Explore factors which inform decisions about who would benefit from palliative care and when palliative care is needed.

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Section 1: Dying and death in contemporary society

Activity 1: Dying and death in 21st century Australia

Thinking Points

1. Think about how death is depicted in the media. Consider television, movies, books and social media.
    - Choose an example and describe:
        - Who is dying?
        - Where are they dying?
        - Why are they dying?
        - Who is involved in the scene?

    - In what ways are media depictions similar or different to your own experiences or observations of where and how people die and how they react to death?

Thinking Points *continued*

2. What historical events and developments have been most influential in shaping attitudes and beliefs about dying and death in developed societies in the 21st century? Consider:
   - Scientific advances
   - Information technology
   - Healthcare developments, reforms and policy
   - Demographic changes
   - Consumerism
   - Social media
   - Mass deaths.

Thinking Points *continued*

3. Some commentators argue that modern Western society is 'death denying' or 'death avoiding'. Provide at least two examples that would:
    - Support this argument
    - Contradict this argument.

    In responding to this question, consider:

    - Any personal experiences you have had in working with or caring for someone with a life-limiting illness
    - Whether you are comfortable (or not) to talk about dying and death and why this is the case
    - Your knowledge of how healthcare resources are allocated and what society prioritises
    - How the media portray dying and death and healthcare in general.

4. Life expectancy is determined by a range of factors (eg, age, gender, health, lifestyle choices and where we live), which can be used to determine the average age at which we are likely to die. Access an online life expectancy calculator (provided by various organisations and life insurance providers) and consider your life expectancy.

    Example: The Death Clock provides a simple calculation based on your answers to six questions.

Tool Used

Outcome

Activity 2: Individual factors influencing dying and death

Thinking Points

1. Think about how you and your immediate family react and respond to dying and death.
    - What factors influenced your reactions when someone close to you died?
    - If you haven't experienced the death of someone close to you, consider how you think it would make you feel.

2. Discuss with others about their experiences or observations of:
    - Practices associated with dying and death in different cultures, age groups, and religions
    - Differences within the same cultural groups.

3. How do you think your culture, age, spiritual beliefs, social networks and past experiences influence the way you will provide care?

Activity 3: Diverse experiences of dying and death

Thinking Points

1. Using the relevant link for your profession, describe the key elements of cultural safety and their implications for the care of people with a life-limiting illness.

2. What would you do to avoid stereotypes and ensure that your practice is culturally safe and encompasses diversity in all of its forms for everyone in your care?

Thinking Points *continued*

3. How can health services create a culturally safe care environment for people who are dying?

4. Find out how to access professional interpreter services in your clinical practice context when caring for people with a life-limiting illness who require this support.

Activity 4: Indigenous Australians

Thinking Points

1. Compare the main causes of death within the Aboriginal and Torres Strait Islander community with the rest of the Australian population. What contributes to these differences?

2. How does understanding the historical journey and its influence on the contemporary society of Aboriginal and Torres Strait Islander peoples help you to provide culturally safe palliative care?

Thinking Points *continued*

3. How can community-based local approaches to palliative care by Aboriginal and Torres Strait Islander health professionals promote culturally safe palliative care?

4. How can loss and trauma potentially prevent Aboriginal and Torres Strait Islander communities from accessing palliative care services?

Activity 5: William’s story

Thinking Points

1. William said he thought he had an outside chance of living to a ‘ripe old age’ and that he doesn’t usually think much about dying.
    - How can these beliefs influence how he responds to a diagnosis of a potential life-limiting illness?

    - What societal and personal factors contributed to his beliefs? Consider in detail:

Scientific developments

Demographic changes

William’s experience with death

William’s age

Thinking Points *continued*

2. How can William's cultural background influence his response to his illness?

3. In what ways would this response differ from a person who comes from a different cultural background?

4. What is your immediate reaction to William's and his wife's situation and their immediate and ongoing needs as a couple – and as individuals?

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Section 2: Caring for people with life-limiting illnesses

Activity 6: What is palliative care?

Thinking Points

1. How do you define quality of life?

2. How does your definition compare with those of other students – or your family and friends?

3. How can the definition of "quality of life" change for a person as their illness progresses?

4. Why is it important for healthcare professionals to understand a person's own perception of quality of life and how it changes over time?

Thinking Points *continued*

5. The World Health Organization's (WHO) definition of palliative care states that 'palliative care' is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications'.

- Describe what is meant by 'early in the course of a life-limiting illness'.

- How does the WHO palliative care definition fit with your understanding of palliative care?

- How would you explain what palliative care is to a patient or their family member?

Activity 7: Who needs palliative care?

Thinking Points

1. Identify the key points distinguishing the following definitions:
   - Palliative care
   - End-of-life care.
2. How do you determine who requires palliative care? Consider:
   - Issues associated with a person's health needs
   - The personal resources and strengths they can draw from.

Thinking Points *continued*

3. Review the illness trajectories and the three associated case studies, answer the following questions:
   - How are these trajectories similar or different to that of a person who is dying as a result of the ageing process?

- How can people's anticipation of death and preparations for end of life be influenced by an understanding of illness trajectories?

- How would you answer the 'Surprise Question' for the patients described in each of these case studies?

Case Study	Answer	Reasons
1. Joan	Yes ○ No ○	
2. Mr Chen	Yes ○ No ○	
3. Hans	Yes ○ No ○	

Activity 8: Understanding people's needs

Thinking Points

1. Think about the principles of palliative care that you've reviewed and how they can be applied to William's situation.
    - What are William's and Gladys' main concerns at this time?
    - How have William's needs changed throughout his illness?
    - What are the key messages the GP provides in relation to William's future care?
    - How did the GP communicate these messages?

Thinking Points *continued*

- How could this interaction be improved to ensure that William and Gladys get optimal support and information about the role of palliative care?

2. Why is it important to consider peoples' preferences when identifying needs at end of life?

3. Refer to the Needs Assessment Tool: Progressive Disease (NAT:PD). Describe:

- The key needs that are assessed

- How the tool can be used in practice.

Thinking Points *continued*

4. What are some of the physical, psychological and social changes that can make a person with a life-limiting illness feel a loss of control?

5. What are the reasons that people often fear pain and other symptoms even when effective symptom management is available?

Activity 9: Personalising palliative care

Thinking Points

1. Compare and contrast the different levels of palliative care needs. Can you think of a person you have cared for who had a life-limiting illness and what level of palliative care need they may have had at that time?

2. What factors can influence the level of need for palliative care services? Consider:
   - Issues associated with a person's health needs
   - The personal resources and strengths they can draw from.

Thinking Points *continued*

3. How might different settings impact on a person's (and their family's) palliative care needs?

Activity 10: Advance care planning

Thinking Points

1. How can an advance care plan help William and his family?

2. Who guides the creation of the advance care plan?

3. What information should be included in William's advance care plan?

Activity 11: William’s illness progresses

Thinking Points

1. What factors influence when specialist palliative care would be helpful for people such as William and Gladys?

2. What decisions do William and Gladys need to make as William’s illness progresses?

Activity 12: Legal and ethical issues and end of life

Thinking Points

1. Refer to the ethical guidelines / code of conduct relevant to your discipline and answer the following questions:
    - How would you respond in a situation where a caregiver has asked you not to inform the person with a life-limiting illness about their diagnosis?
    - How do you respond to a person who tells you that they have 'had enough' and no longer want treatment?

Thinking Points *continued*

- How would you respond if someone requests that you help them end their life early?

2. Search recent literature and identify definitions of the term ‘futile treatment’ and ‘non-beneficial’ treatment.

Futile treatment

Non-beneficial treatment

Thinking Points *continued*

3. In what ways can perceptions of futility differ between the person with a life-limiting illness, families and carers and health professionals, and between different health professionals?

4. Refer to the Euthanasia and Assisted Dying page from QUT End of Life Law in Australia. Consider how the Victorian Voluntary Assisted Dying Law affects the provision of palliative care.

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Section 3: Ensuring quality palliative care

Activity 13: Quality palliative care in Australia

Thinking Points

1. Review the National Palliative Care Standards 1–6 (pages 13–18). Reflect on the specific strategies that you would apply to meet these standards when caring for people affected by life-limiting illnesses.

	Standard	Strategies
Standard 1	Initial and ongoing assessment incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs.	
Standard 2	The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan.	
Standard 3	The person's family and carers needs are assessed and directly inform provision of appropriate support and guidance about their role.	
Standard 4	The provision of care is based on the assessed needs of the person, informed by evidence and is consistent with the values, goals and preferences of the person as documented in their care plan.	
Standard 5	Care is integrated across the person's experience to ensure seamless transitions within and between services.	

Thinking Points *continued*

	Standard	Strategies
Standard 6	Families and carers have access to bereavement support services and are provided with information about loss and grief.	
Standard 7	The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care and end-of-life care.	
Standard 8	Services are engaged in quality improvement and research to improve service provision and development.	
Standard 9	Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles.	

Thinking Points *continued*

2. Maintaining dignity is a core value in palliative care. Within your scope of practice, what are some strategies that you would undertake to ensure a person's dignity is maintained?

3. The impact of asking, "What do I need to know about you as a person to give you the best care possible?" can be helpful in planning a person-centred approach to care. Reflect on when you may be able to include this in your daily practice.

Activity 14: Evidence-based palliative care

Thinking Points

1. Visit the CareSearch website, select a topic of interest and review the strongest evidence available via the PubMed search. Describe how this resource can benefit your practice.

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Section 4: Reflections on what you have learnt

It is essential for all health care professionals to develop the capacity for reflection and self-evaluation of their professional and personal experiences and consider how this impacts themselves and others.

Consider the module you have just completed – Principles of Palliative Care and reflect upon the following questions to assist with your ongoing development:

1. What key points have you learnt from the activities in this module that will help you in providing care for people with life-limiting illnesses and their families?

2. What specific strategies do you plan to incorporate as a graduate healthcare professional?

3. Do you see any difficulties using what you've learnt here as part of your practice as a healthcare professional? If so, what strategies can you use to address these difficulties?