PALLIATIVE CARE QUESTIONS AND ANSWERS

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Questions and Answers

Question 1

ST ELIZA SCHOOL OF NURSING AND MIDWIFERY - NO.70

- Define palliative care according to WHO.

- Outline 10 aims of palliative care.

- List 5 challenges facing palliative care in Uganda?

ANSWER: Examination Script

According to the World Health Organization (WHO, 2002 definition as cited in PDF, and updated definitions maintain similar core principles): Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

1. Provide Relief from Pain and Other Distressing Symptoms: Such as nausea, fatigue, breathlessness, anxiety, using pharmacological and non-pharmacological methods.
2. Affirm Life and Regard Dying as a Normal Process: Palliative care does not aim to hasten or postpone death but to support the patient through their natural life course.
3. Integrate the Psychological and Spiritual Aspects of Patient Care: Addressing emotional, social, and spiritual needs alongside physical symptoms.
4. Offer a Support System to Help Patients Live as Actively as Possible Until Death: Focusing on maximizing function, independence, and engagement in meaningful activities.
5. Offer a Support System to Help the Family Cope During the Patient s Illness and in Their Own Bereavement: Providing counseling, practical support, and bereavement care for family members.
6. Enhance Quality of Life: This is a primary goal, which may also positively influence the course of illness.
7. Use a Team Approach to Address the Needs of Patients and Their Families: Involving doctors, nurses, social workers, counselors, spiritual advisors, volunteers, and other professionals.
8. Improve Communication: Facilitate open and honest communication between patients, families, and the healthcare team about goals of care, prognosis, and end-of-life issues. (PDF point: "provide effective communication which is concerned with healing rather than curing whereby healing is all about relationship with self, others, environment, God and pain control.")
9. 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.

10. Neither Hasten nor Postpone Death: Focus on providing peace and comfort. (PDF point: "To neither hasten nor postpone death. if someone is provided with peace and comfort, it improves the quality of life.")

11. Address Needs of Patients and Families Including Bereavement Counseling: Utilizing a team approach. (PDF point).

12. Work in Conjunction with Other Therapists: To prolong life in the course of illness. (PDF point).

1. Limited Resources: Insufficient funding for palliative care services, including medications (especially opioids for pain relief), equipment, and trained personnel.

2. Shortage of Trained Palliative Care Personnel: Lack of specialized healthcare professionals (doctors, nurses, social workers) trained in palliative care principles and practices across the country, especially in rural areas.

3. Poor Accessibility, Especially in Rural Areas / Poor Infrastructures: Many patients who need palliative care live in remote areas with limited access to health facilities that can provide such services. Poor roads and transport make it difficult for patients to reach services or for teams to conduct home visits.

4. Lack of Awareness and Misconceptions: Limited understanding among the general public, and sometimes among healthcare professionals, about what palliative care is, its benefits, and when it should be initiated. Misconceptions about opioid use for pain relief (e.g., fear of addiction).

5. Weak Health Systems and Integration: Palliative care is often not well integrated into the existing healthcare system. Lack of national policies consistently implemented, or poor coordination between different levels of care.

6. Cultural and Social Barriers: Cultural beliefs about death, dying, and pain management can sometimes pose challenges. Preference for traditional healers over formal palliative care. (PDF point: "Many people prefer traditional healers to palliative care in Uganda.")

7. Limited Availability of Essential Medicines (especially Opioids): Regulatory hurdles, stock-outs, or logistical challenges in distributing controlled medicines like morphine can hinder effective pain management.

8. Political Instabilities (as mentioned in PDF more generally): While a broader issue, periods of instability can disrupt health services, including palliative care.

9. Corruption (as mentioned in PDF more generally): Can divert resources intended for palliative care or other health services.

Question 2

JINJA SCHOOL OF NURSING AND MIDWIFERY - NO.71

- Define the following terms. Mourning

- Grief
- Bereavement
- Living will
- An analgesic ladder.

- Outline 6 principles of palliative care.

- Mention six steps of breaking bad news according to spikes model.

ANSWER: Examination Script

i. Mourning: Mourning is the outward expression of grief and sorrow following a loss, particularly the death of a loved one. It involves the culturally defined social customs, rituals, and behaviors that individuals and communities engage in to cope with bereavement, such as wearing black, holding funerals or memorial services, observing periods of seclusion, or specific religious practices. Mourning is the public display of grief.

ii. Grief: Grief is the internal, personal, and multifaceted response to loss. It encompasses a wide range of emotional (e.g., sadness, anger, guilt, loneliness), physical (e.g., fatigue, sleep disturbances, appetite changes), cognitive (e.g., disbelief, confusion, preoccupation with the deceased), behavioral, and spiritual reactions an individual experiences after a significant loss, most commonly the death of a loved one, but also other losses like loss of health, job, or relationship.

iii. Bereavement: Bereavement is the objective state or period of sadness, grief, and mourning that occurs after experiencing the death of a loved one or a significant loss. It is the situation of having lost someone or something important, and the process of adjusting to that loss.

iv. Living Will: A living will is a type of advance directive, which is a legal document in which a person specifies their wishes regarding medical treatment they would or would not want to receive if they become terminally ill or permanently unconscious and are unable to communicate their decisions themselves. It typically outlines preferences for life-sustaining treatments like mechanical ventilation, artificial nutrition and hydration, or resuscitation.

v. An Analgesic Ladder (WHO Analgesic Ladder): The WHO Analgesic Ladder is a guideline developed by the World Health Organization for the pharmacological management of cancer pain, though its principles are often applied to other types of chronic pain. It proposes a stepwise approach to pain relief: Step 1 (Mild Pain): Non-opioid analgesics (e.g., paracetamol, NSAIDs like ibuprofen) +/- adjuvant drugs. Step 2 (Mild to Moderate Pain persisting or increasing): Weak opioids (e.g., codeine, tramadol) +/- non-opioid analgesics +/- adjuvant drugs. Step 3 (Moderate to Severe Pain persisting or increasing): Strong opioids (e.g., morphine, fentanyl, oxycodone) +/- non-opioid analgesics +/- adjuvant drugs. The principle is to start at the appropriate step based on pain severity and escalate if pain is not controlled. Adjuvant drugs (e.g., antidepressants, anticonvulsants, corticosteroids) are used to manage specific types of pain or side effects. Illustrating the WHO Analgesic Ladder with its 3 steps

1. Patient Centered: Palliative care revolves around the patient and their family, supporting them throughout different stages of the illness. The focus is on maintaining hope with realistic goals to help the patient and families cope appropriately through different phases.

2. Appropriate Ethical Consideration: Palliative care involves navigating various ethical issues that arise, ensuring decisions are made fairly and ethically. Seek to do good or do no harm. Patients rights must be considered. Balance doing what s best for the patient while respecting their rights and autonomy.

3. Continuum of Treatment: Palliative care begins from the time of diagnosis and extends beyond the patient s passing. This involves management of pain and other symptoms. It includes providing bereavement care for the family after death.

4. Teamwork and Partnership: Palliative care requires an interdisciplinary team to effectively address the diverse needs of patients, as no single profession can address all issues causing total pain. Team members share challenges and plan effective management using their skill mix. A palliative care team includes: Nurses Doctors Social workers Religious leaders Teachers Community health providers Others as appropriate.

5. Holistic Care Approach: Holistic care treats the patient as a whole person, focusing on physical, psychological (emotional), social, and spiritual care, not just the medical case. Psychological and emotional support should be available for caregivers, patient, family members, community volunteers, and professional workers (health workers, counselors, social workers) before, during, and after periods of caregiving.

S - Setting up the Interview: Privacy: Choose a private, quiet, comfortable setting where you won't be interrupted. Involve Significant Others: Ask the patient if they want anyone else present (family, friend). Sit Down: Shows you are not rushed. Ensure patient is also comfortable. Connection: Make a connection with the patient (e.g., eye contact, rapport). Manage Time and Interruptions: Allocate adequate time and minimize interruptions.

P - Perception: Assessing the Patient's Perception: Before giving information, find out what the patient already knows or suspects about their condition. Use open-ended questions like, "What have you been told so far about your illness?" or "What is your understanding of why we did the test?" Reason: Helps to gauge their level of understanding, identify misinformation, and tailor the news to their current knowledge.

I - Invitation: Obtaining the Patient's Invitation (How much do they want to know?): Ask the patient how much information they would like to know about their diagnosis, prognosis, or treatment options. Respect their right to know or not to know (within limits). Example questions: "How much information would you like me to give you about the results?" or "Would you like me to tell you the full details, or would you prefer a summary?" Reason: Respects patient autonomy and allows them to control the flow of information.

K - Knowledge: Giving Knowledge and Information to the Patient: Share the bad news clearly, directly, and honestly, but with empathy and sensitivity. Use simple, understandable language, avoiding medical jargon. Give information in small chunks and check for understanding frequently. Start with a warning shot, e.g., "I'm afraid I have some serious news to discuss." Reason: Provides essential information for decision-making and coping.

E - Emotions: Addressing the Patient's Emotions with Empathic Responses: Acknowledge and validate the patient's emotional reactions (e.g., shock, sadness, anger, fear, denial). Listen quietly and attentively. Use empathic statements like, "I can see this is very upsetting news for you," or "This must be very difficult to hear." Offer comfort and support. Allow time for silence and tears. Reason: Shows compassion and helps the patient begin to process the news.

S - Strategy and Summary: Planning for the Future and Summarizing: Discuss a clear plan for the next steps (treatment options, further tests, referrals, support services). Involve the patient in decision-making if appropriate. Summarize the key information discussed and check for understanding. Offer realistic hope (e.g., about symptom control, quality of life, support available) without giving false reassurance. Schedule a follow-up appointment. Provide contact information for further questions. Reason: Provides a clear path forward, reduces uncertainty, and ensures the patient feels supported.

Question 3

RUBAGA HOSPITAL NURSING AND MIDWIFERY TRAING SCHOOLS - NO.71

- Outline 10 myths surrounding use of morphine in pain management.

- Describe the non-pharmacological methods of managing pain in cancer patients.

ANSWER: Examination Script

Myth 1: Morphine is only for dying patients / "End-of-life" drug. Fact: Morphine is used to manage severe pain at any stage of a serious illness, not just at the very end of life. Effective pain control can improve quality of life and allow patients to be more active.

Myth 2: Morphine always causes addiction (psychological dependence). Fact: When used appropriately for pain relief under medical supervision, addiction is rare. Physical dependence (experiencing withdrawal if stopped suddenly) and tolerance (needing higher doses over time for same effect) can occur with long-term use, but these are different from addiction.

Myth 3: Morphine will hasten death / "Euthanasia by another name." Fact: When used correctly to relieve pain, morphine does not hasten death. In fact, unrelieved severe pain can cause stress and hasten decline. The goal is comfort.

Myth 4: Morphine always causes severe respiratory depression (stops breathing). Fact: Respiratory depression is a potential side effect, but it is rare when morphine is started at a low dose and titrated (adjusted) carefully upwards according to pain levels. Pain itself is a physiological antagonist to opioid-induced respiratory depression. Patients on stable doses develop tolerance to this effect.

Myth 5: If you start morphine, you can't increase the dose later if pain worsens (tolerance develops too quickly). Fact: While tolerance can develop, the dose of morphine can usually be increased safely and effectively as needed to manage increasing pain. There is often no maximum "ceiling" dose for morphine if titrated properly.

Myth 6: Morphine causes intolerable side effects like constant drowsiness or nausea. Fact: Drowsiness and nausea can occur, especially when starting morphine or increasing the dose, but these side effects often lessen or disappear within a few days as the body adapts. They can also be managed with other medications (e.g., anti-emetics).

Myth 7: Morphine will make the patient "doped up" or unable to function. Fact: When the dose is appropriate for the level of pain, patients usually feel more comfortable, less distressed, and may be able to function better. Excessive sedation usually means the dose is too high or needs adjustment.

Myth 8: All pain can be controlled by morphine alone. Fact: Morphine is very effective for many types of pain, but some pain (e.g., neuropathic pain) may require adjuvant analgesics (like anticonvulsants or antidepressants) in addition to or instead of opioids.

Myth 9: Taking morphine is a sign of weakness or giving up. Fact: Pain is a physiological symptom that deserves treatment. Using morphine to control severe pain is a way to improve quality of life and comfort, not a sign of weakness.

Myth 10: Once you start morphine, you have to take it for life. Fact: If the cause of pain is resolved or reduces (e.g., after successful cancer treatment), the dose of morphine can often be gradually reduced and sometimes stopped, under medical supervision.

Myth 11: Oral morphine is not as effective as injectable morphine. Fact: Oral morphine (especially sustained-release preparations) is effective for managing chronic pain and is often the preferred route for convenience. The dose may need to be adjusted due to bioavailability differences, but effectiveness can be achieved.

Physical Therapies: Heat and Cold Application: Warm compresses or heating pads can relax sore muscles and reduce stiffness. Cold packs can numb an area and reduce inflammation or swelling. Massage: Gentle massage can help relax tense muscles, improve circulation, reduce anxiety, and promote a sense of well-being. Avoid massage directly over tumor sites or areas of skin breakdown. Transcutaneous Electrical Nerve Stimulation (TENS): A device that delivers small electrical impulses to nerve endings through electrodes placed on the skin near the painful area. Can help block pain signals. Physiotherapy / Exercise: Gentle exercises, stretching, and range-of-motion activities prescribed by a physiotherapist can help maintain mobility, reduce stiffness, improve strength, and reduce pain. Positioning and Support: Using pillows or supports to maintain comfortable body alignment and reduce pressure on painful areas. Acupuncture / Acupressure: Traditional Chinese medicine techniques involving insertion of fine needles (acupuncture) or applying pressure (acupressure) to specific points on the body to relieve pain.

Psychological and Mind-Body Therapies: Relaxation Techniques: Deep breathing exercises, progressive muscle relaxation, meditation, mindfulness to reduce tension, anxiety, and pain perception. Guided Imagery / Visualization: Focusing the mind on pleasant, calming images or scenes to distract from pain and promote relaxation. Distraction: Engaging in enjoyable activities that take the mind off the pain, such as listening to music, reading, watching movies, hobbies, or talking with others. Cognitive Behavioral Therapy (CBT): Helps patients identify and change negative thought patterns and behaviors related to pain, and develop coping strategies. Hypnosis / Self-Hypnosis: Can help alter pain perception and promote relaxation. Biofeedback: Learning to control certain physiological responses (like muscle tension or heart rate) with the help of electronic monitoring, to reduce pain. Music Therapy / Art Therapy: Using creative expression to reduce stress, improve mood, and provide an outlet for emotions related to pain and illness.

Spiritual and Social Support: Spiritual Care: Addressing spiritual or existential distress through prayer, meditation, consultation with religious leaders or spiritual counselors. Support Groups: Connecting with other cancer patients to share experiences and coping strategies. Family and Social Support: Encouraging involvement of loved ones in providing comfort and support.

Lifestyle and Environmental Modifications: Creating a Comfortable Environment: E.g., comfortable bed, quiet room, pleasant surroundings. Pacing Activities: Balancing rest and activity to conserve energy and avoid overexertion that might worsen pain. Adequate Sleep: Promoting good sleep hygiene.

Question 4

WAKISO COMPREHENSIVE INSTITUTE OF HEALTH SCIENCES - NO.72

- Define the term pain.

- Outline ten pain experienced by HIV/AIDS patients.

- Describe the WHO analgesics ladder.

ANSWER: Examination Script

Answer: (Researched)

a) Define the term Pain:

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. (This is the widely accepted definition from the International Association for the Study of Pain - IASP). Key aspects of this definition: Pain is subjective: It is a personal experience. If a person says they are in pain, they are in pain. It has both sensory (physical sensation) and emotional components. It can be caused by actual tissue damage (e.g., an injury, inflammation) or potential tissue damage (e.g., prolonged pressure). Pain can also be described in terms of damage even if no clear physical cause is found (e.g., some types of neuropathic pain or psychogenic pain).

b) Outline Ten Types of Pain Experienced by HIV/AIDS Patients:

Pain is a very common symptom in people living with HIV/AIDS (PLWHA) and can occur at any stage of the disease. It can be caused by the HIV infection itself, opportunistic infections, cancers, side effects of antiretroviral therapy (ART) or other medications, or co-existing conditions.

1. Peripheral Neuropathy Pain: A very common type. Nerve damage, often in the hands and feet, causing burning, tingling, numbness, pins and needles, or shooting pain. Can be caused by HIV itself or by certain older ART drugs (e.g., stavudine, didanosine).

2. Musculoskeletal Pain: Arthralgia (Joint Pain): Can be due to HIV-associated arthritis, opportunistic infections affecting joints, or side effects of medications. Myalgia (Muscle Pain): Generalized aches or localized muscle pain. Bone Pain: Can be due to osteoporosis (related to HIV or ART), or from cancers like lymphoma.

3. Headache: Can be frequent and severe. Causes include opportunistic infections of the brain (e.g., cryptococcal meningitis, toxoplasmosis), CNS lymphoma, tension headaches, migraines, or medication side effects.

4. Abdominal Pain: Can be caused by opportunistic infections of the gastrointestinal tract (e.g., CMV colitis, cryptosporidiosis, MAI), pancreatitis (medication side effect), hepatosplenomegaly, or intra-abdominal cancers.

5. Oral and Esophageal Pain: Painful swallowing (odynophagia) or mouth pain due to opportunistic infections like oral candidiasis (thrush), herpes simplex ulcers, cytomegalovirus (CMV) ulcers in the esophagus, or aphthous ulcers.

6. Skin Pain / Dermatological Pain: Painful skin lesions or rashes from conditions like herpes zoster (shingles), severe fungal infections, Kaposi's sarcoma, or drug reactions.

7. Pain Associated with Cancers: AIDS-defining cancers like Kaposi's sarcoma, non-Hodgkin's lymphoma, and cervical cancer can cause pain due to tumor growth, nerve compression, or bone involvement.

8. Visceral Pain: Pain originating from internal organs, often poorly localized, cramping, or aching. Can be due to organ involvement by infection or tumor.

9. Procedural Pain: Pain related to medical procedures like biopsies, lumbar punctures, or IV insertions.

10. Psychosocial / Emotional Pain (often coexists and exacerbates physical pain): Distress related to stigma, discrimination, loss, anxiety, depression which can worsen the perception and experience of physical pain.

11. Pain from Medication Side Effects (other than neuropathy): Some ART drugs can cause headaches, abdominal discomfort, or other painful side effects.

12. Post-Herpetic Neuralgia: Persistent nerve pain after an episode of herpes zoster (shingles).

The WHO Analgesic Ladder is a guideline developed by the World Health Organization, initially for the pharmacological management of cancer pain, but its principles are widely applied to other types of acute and chronic pain. It advocates a stepwise approach to selecting analgesics based on the severity of pain. The goal is to provide adequate pain relief while minimizing side effects.

The Three Steps: Step 1: For Mild Pain (Pain score 1-3 out of 10) Drug Choice: Non-opioid analgesics such as Paracetamol (Acetaminophen) or a Non-Steroidal Anti-Inflammatory Drug (NSAID) like Ibuprofen, Diclofenac, or Aspirin. Adjuvants: +/- Adjuvant drugs if indicated (e.g., for neuropathic pain, bone pain, or to manage side effects). Step 2: For Mild to Moderate Pain (Pain score 4-6 out of 10), or if pain persists or increases despite Step 1 drugs. Drug Choice: Weak opioids such as Codeine or Tramadol. These are often given in combination with a non-opioid analgesic (like paracetamol). Adjuvants: +/- Non-opioid analgesics +/- Adjuvant drugs. Step 3: For Moderate to Severe Pain (Pain score 7-10 out of 10), or if pain persists or increases despite Step 2 drugs. Drug Choice: Strong opioids such as Morphine (gold standard), Fentanyl, Oxycodone, Hydromorphone, Methadone, Pethidine (less preferred for chronic use). Adjuvants: +/- Non-opioid analgesics +/- Adjuvant drugs.

Key Principles of Using the Ladder: By the Mouth: Oral route is preferred whenever possible for ease of administration. By the Clock: Analgesics for persistent pain should be given regularly (around the clock) to maintain consistent pain relief, rather than only "as needed" (PRN) initially. PRN doses can be used for breakthrough pain. By the Ladder: Start with drugs appropriate for the pain severity and move up (or down) the ladder as needed. For the Individual: Tailor the choice of drug, dose, and route to the individual patient's needs, response, and side effects. Regular assessment of pain and adjustment of treatment is crucial. Attention to Detail: Includes managing side effects of analgesics (e.g., constipation with opioids) and using adjuvant drugs appropriately.

Question 5

MUKONO DIOCESES SCHOOL OF NURSDING AND MIDWIFERY - NO.73

- Define advanced directive.

- Outline ten contents of a living will.

- List 7 benefits of a living will in palliative care.

ANSWER: Examination Script

An advance directive is a legal document (or a set of documents) that allows a competent adult to state their preferences and instructions regarding future medical treatment, or to appoint a healthcare proxy (surrogate decision-maker), in the event they become unable to make or communicate their own healthcare decisions due to illness or incapacity. It helps ensure that a person's wishes about their medical care are known and respected if they lose decision-making capacity. A living will and a durable power of attorney for healthcare are common types of advance directives.

1. Identification of the Declarant: Full legal name, address, and date of birth of the person making the living will.

2. Statement of Intent / Declaration: A clear statement that the document reflects their wishes regarding medical treatment under specific future circumstances when they are unable to make decisions.

3. Definition of Terminal Condition / Persistent Vegetative State: Specifies the medical conditions under which the living will becomes effective (e.g., incurable terminal illness, permanent unconsciousness where recovery is judged medically hopeless).

4. Preferences for Life-Sustaining Treatments: Specific instructions about which life-sustaining treatments they would want or not want, such as: Cardiopulmonary Resuscitation (CPR). Mechanical Ventilation (Breathing Machine). Artificial Nutrition and Hydration (Tube Feeding, IV Fluids). Dialysis. Antibiotics (for life-threatening infections in a terminal state). Blood Transfusions.

5. Wishes Regarding Palliative Care / Comfort Measures: Often states a desire to receive all measures necessary for comfort and pain relief, even if life-sustaining treatments are withdrawn or withheld.

6. Appointment of a Healthcare Proxy/Agent (sometimes part of a separate Durable Power of Attorney for Healthcare, but can be referenced): Naming a specific person to make healthcare decisions on their behalf if they are incapacitated, consistent with the living will.

7. Signatures and Witnessing: The document must be signed by the declarant and usually witnessed by a specific number of individuals (who are typically not relatives, beneficiaries, or healthcare providers involved in their care) to be legally valid, according to local laws.

8. Date of Execution: The date the living will was signed.

9. Revocation Clause: Information on how the living will can be changed or revoked by the declarant while they are still competent.

10. Organ and Tissue Donation Preferences (Optional): Some living wills may include statements about willingness to donate organs or tissues.

11. General Statements about Quality of Life: May include personal values or beliefs about what constitutes an acceptable quality of life that should guide decisions.

1. Promotes Patient Autonomy and Self-Determination: Allows individuals to make their own choices about end-of-life care and ensures their wishes are respected even when they can no longer communicate them.

2. Reduces Burden on Family Members: Relieves family members of the difficult responsibility of making life-and-death decisions without knowing the patient's preferences, which can reduce guilt and conflict among family.

3. Provides Clear Guidance to Healthcare Providers: Offers clear instructions to doctors and nurses regarding the patient's wishes for treatment, helping them provide care that aligns with the patient's values and avoiding unwanted interventions.

4. Prevents Unwanted or Futile Medical Interventions: Can help avoid aggressive or burdensome treatments that may not improve quality of life or prolong life meaningfully, and which the patient would not have wanted.

5. Facilitates Focus on Comfort and Quality of Life: By specifying limits on life-sustaining treatments, a living will can help shift the focus of care towards palliative measures aimed at comfort, pain relief, and dignity.

6. Reduces Conflict and Disputes: Can minimize disagreements among family members or between family and healthcare providers about treatment decisions by making the patient's wishes known.

7. Enhances Peace of Mind for the Patient: Knowing that their end-of-life wishes are documented and likely to be followed can provide peace of mind to the individual while they are still able to make these decisions.

8. Encourages Important Conversations: The process of creating a living will often encourages individuals to have important conversations with their loved ones and healthcare providers about their values and end-of-life preferences.