Handout #1 – WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Enhances quality of life, and may also positively influence the course of illness
- 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

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. (World Health Organization) WHO's definition of palliative care appropriate for children and their families is as follows, and the principles apply to other pediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind, and spirit, and involves giving support to the family
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; and it can be successfully implemented even if resources are limited
- It can be provided in tertiary care facilities, in community health centers and even in children's homes

Handout #2 – TIPS for the Nursing Assistant's Role in Pain Management

HPNA Hospice and Palliative Nurses Association

TIPS for the Nursing Assistant's Role in Pain Management

The nursing assistant spends a significant amount of time with the patient and family, and plays an important role in pain management. When the patient or family reports pain or pain is observed, the nursing assistant must report it to the nurse, who can evaluate the patient and revise the plan of care.

See also the TIPS Sheet on *Recognizing Pain* and *Recognizing Pain In Patients with an Inability to Communicate Verbally*, which are available at www.hpna.org.

The nurse needs to be consulted before a nursing assistant begins any of the following methods of pain relief.

- Breathing techniques
- Application of heat/cold
- Aromatherapy
- Gentle massage (back, hand, foot)

The nurse may suggest that the nursing assistant help the patient and/or family with one of the following methods to treat pain as described in the plan of care. Some of these treatments may need instruction from the nurse before the nursing assistant begins them.

- Repositioning
- Distraction (pets, social support, quiet listening, laughter, reminiscing)
- Prayer or spiritual reading
- Music

Report to the nurse the patient's use of ordered pain-relieving medications.

Other HPNA TIPs Sheets are available at www.hpna.org.

Reference

Ferrell B, Coyle N. *Textbook of Palliative Nursing*. 2nd ed. New York, NY: Oxford University Press; 2006.

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Activity #1 – Pain/Interventions Examples

1. Have each student write down 2-3 things that they feel would/could cause pain.

2. Encourage them to think about pain outside of physical pain as well.

3. Have the students write down a suggestion as to how to deal with that pain/ease that pain.

An example to describe is: A 28-year-old woman has a brain tumor and has just discovered she is pregnant. She doesn't know if she will live long enough to carry the child or see the child for long after he/she is born. She has always been faithful and a servant in her church. She now refuses to go to church and blames God for this situation.

What could the aide do in this situation? Listen, listen, and listen some more. Be supportive but never give answers such as, "it will all be ok." Notify your supervisor and the rest of the team. They need to be aware of where she is with grieving so that intervention can take place appropriately and with the appropriate team member (e.g. chaplain).

Handout #3 – The 5 Stages of Grief

The **Kübler-Ross model,** commonly known as the **five stages of grief**, was first introduced by Elisabeth Kübler-Ross in her 1969 book, *On Death and Dying*.

The progression of states is:

1. **Denial** – "I feel fine" "This can't be happening, not to me." Denial is usually only a temporary defense for the individual. This feeling is generally replaced with heightened awareness of situations and individuals that will be left behind after death.
2. **Anger** – "Why me? It's not fair!" "How can this happen to me?" *"Who is to blame?"* Once in the second stage, the individual recognizes that denial cannot continue. Because of anger, the person is difficult to care for due to misplaced feelings of rage and envy. Any individual that symbolizes life or energy is subject to projected resentment and jealousy.
3. **Bargaining** – "Just let me live to see my children graduate," "I'll do anything for a few more years," "I will give my life savings if..." The third stage involves the hope that the individual can somehow postpone or delay death. Usually, the negotiation for an extended life is made with a higher power in exchange for a reformed lifestyle. Psychologically, the individual is saying, "I understand I will die, but if I could just have more time..."
4. **Depression** – "I'm so sad, why bother with anything?" "I'm going to die... What's the point?" "I miss my loved one, why go on?" During the fourth stage, the dying person begins to understand the certainty of death. Because of this, the individual may become silent, refuse visitors and spend much of the time crying and grieving. This process allows the dying person to disconnect oneself from things of love and affection. It is not recommended to attempt to cheer up an individual who is in this stage. It is an important time for grieving that must be processed.
5. **Acceptance** – "It's going to be okay." "I can't fight it, I may as well prepare for it." In this last stage, the individual begins to come to terms with their mortality or that of their loved one.

Kübler-Ross originally applied these stages to people suffering from terminal illness and later to any form of catastrophic personal loss (job, income, freedom). This may also include significant life events such as the death of a loved one, divorce, drug addiction, the onset of a disease or chronic illness, an infertility diagnosis, as well as many tragedies and disasters.

Kübler-Ross claimed these steps do not necessarily come in the order noted above, nor are all steps experienced by all patients, though she stated a person will always experience at least two. Often, people will experience several stages in a roller coaster effect—switching between two or more stages, returning to one or more several times before working through it.

Significantly, people experiencing the stages should not force the process. The grief process is highly personal and should not be rushed, nor lengthened, based on an individual's imposed time frame or opinion. One should merely be aware that the stages will be worked through and the ultimate stage of acceptance will be reached.

However, there are individuals who struggle with death until the end. Some psychologists believe that the harder a person fights death, the more likely they are to stay in the denial stage. If this is the case, it is possible the ill person will have more difficulty dying in a dignified way. Other psychologists state that not confronting death until the end is adaptive for some people. Those who experience problems working through the stages should consider professional grief counseling or support groups.

Activity #2 – Examples of the 5 Stages of Grief

After reading and discussing the 5 stages of grief, have each student write an example of a situation where a person would be in one of those stages.

How would the person in that example transition through/out of that stage?

Discuss the student's examples.