Dealing With the Death of Your Patient

Learning objectives:

By the end of this lesson, caregivers will be able to:

1. Understand the importance of grieving in a healthy manner;
2. Understand the value of faith as a support during the grieving process;
3. Demonstrate an understanding of grief and bereavement;
4. Demonstrate an understanding of the Stages of Grief and the Four Tasks of Grief;
5. Be able to identify three positive coping strategies for dealing with patient loss; and
6. Define the concept of hospice.

Glossary

Grief	A natural process and normal reaction to loss; The natural healing response to loss.
Anticipatory (pre) Grief	Grief that exists before the death; or when death is expected.
Cumulative (or collective) Grief	Grief resulting from previous losses which complicates feelings in dealing with death.
Bereavement	The period of time following the death of a loved one.
Palliative Care	Care that relieves or soothes, rather than cures, the symptoms of a disease or disorder. The intention of palliative care is to make patients as comfortable as possible when a cure is not possible.
Hospice	Hospice is a term that comes from medieval times. It was a place where travelers, pilgrims and the sick, wounded or dying could find rest and comfort. Today's hospice offers a program of care to patients and families facing a terminal illness. Hospice is primarily a *concept of care*, not a specific place of care, and often takes place in patients' homes.
Stages of Grief	The stages of grief are phases that mourners move through as they deal with loss: *Denial and Isolation, Anger, Bargaining, Depression, and Acceptance.*
Tasks of Grief	The Tasks of Grief are similar to Stages of Grief, and represent concrete steps toward working through grief: *Accepting* the reality of the loss; Feeling the pain of grief*; Adjusting* to a new situation without the deceased; Withdrawing emotionally and *reinvesting* in new relationships.

One purpose of dealing with grief is to allow us to invest in the lives of others that need the same comfort.

Home Care Aides Grieve Too

Home care aides work in a setting very different from many in the health care field. Aides often work in relative isolation, with little daily contact with coworkers or supervisors. The loss of a patient or friend is difficult enough in supportive surroundings, but with no one to talk to or share with, it can be devastating. In addition, some home care aides work in a hospice setting, which results in frequent exposure to patient death.

It is important for you to grieve the deaths of your patients. This program will help you explore and recognize your personal feelings and fears about death as well as help you to understand ways to deal with your grief. Each of us needs to come to some form of personal means of dealing with death. Culture, gender, personality, and past experience with grief all impact the way you might deal with loss. Those who can not come to terms with patient loss often become "burned out" and leave the health care field.

What is Grief?

Grief is a normal reaction to a loss as well as a healing response as one adjusts to that loss. Grieving people will feel many emotions including sadness, anger, guilt, anxiety, loneliness, fatigue, helplessness, shock, and numbness. Some experience loss of appetite, sleeplessness, or social withdrawal. Crying is normal. Do not be alarmed if some of these happen to you. Expressing emotions is a healthy, normal part of the grieving process.

Under the mask of being "professional," caregivers may protect themselves by going numb and disconnecting from other patients. This is not healthy and does not allow you to heal from grief—it just delays the feelings.

Feeling Grief Before the Patient Dies

Being a caregiver is a difficult job. While the potential death of a patient is always a possibility in any form of health care, in home care and hospice, it is more frequent. This can be difficult for many caregivers, who frequently come to care a great deal about the patients they take care of—sometimes for years. Often patients and caregivers look at each other as members of an extended family. When the patient dies, the caregiver grieves.

When we think of grief we generally think of the process and feelings we experience after someone dies. In reality we begin this process on the day someone is diagnosed with a life threatening illness, or when someone "takes a turn for the worse," or starts "going downhill."

When patients have been diagnosed with a terminal illness, or when a death is expected, *anticipatory grief* occurs. For the sake of this program, we're going to call it pre-grief. This can be very difficult emotionally for the patient, the family, and the caregiver as they all try to cope with the impending death. A caregiver needs to be aware of the needs of all—the patient, the patient's family, and their own feelings.

The most common concern about pre-grief is that it can result in caregivers and loved ones withdrawing from the dying person. They can not deal with their grief, nor that of the dying loved one. This may cause tremendous difficulty for the dying person who feels abandoned. The stress of caring for a dying individual added to pre-grief can cause numbness, which is often misinterpreted as not caring. If the period of time before the death occurs is extended, family members and caregivers can become angry, and want the death "to be over with." This can create guilt, which creates more stress.

It is normal for caregivers to feel many emotions at this time, including sadness, frustration, guilt, anger, fear, and even loneliness, especially if they have no one to talk to about their feelings.

Cumulative or Collective Grief

Often, anticipated loss serves as a reminder of past losses. If there has not be a satisfactory closure to similar, previous losses, a cumulative effect occurs, which can be extremely difficult. This is called *cumulative grief*. An example would be that if a patient reminds you of your deceased mother, the loss of this patient would serve as a powerful reminder of your own grief.

Bereavement

Bereavement is the period of time during which the mourner goes through the grieving process. Literally, it means "state of sorrow." "The Bereaved" is a term often used to refer to someone who has suffered the loss of a loved one.

The Grief Process

Grief is thought to be a process that goes through stages. Dr. Elizabeth Kubler-Ross was one of the first to write about this. Her work is based on research with patients with terminal illness, but both patients confronting their death and mourners dealing with loss go through similar stages.

The Five Stages of Death and Grief

from "On Death and Dying" by Dr. Elizabeth Kubler-Ross

Patient Behavior		Bereaved Behavior
Denial	**Needed Response**	**Denial**
Patient seeks frantically for a favorable diagnosis, cannot accept truth.	Understand why patient is grabbing at straws, be patient, willing to listen	Creates defense, avoids family, friends, loved ones.
Anger	**Needed Response**	**Anger**
"WHY ME?" Patient may be bitterly angry, envy those who are well, and complain incessantly.	Understand the patient is angry over their loss, and feels cheated. Treat patient with respect and compassion, not by returning the anger.	Anger at others for living when loved one cannot. Anger at person who died for leaving.
Bargaining	**Needed Response**	**Bargaining**
Patient tries to bargain with God, promises to be good in exchange for time and freedom from pain.	If the patient's bargain is revealed, listen to it with respect. This stage lasts a short time.	Promises to God asking for return of loved one.
Depression	**Needed Response**	**Depression**
The patient grieves, and mourns approaching death.	Attempts to cheer up mean little. The patient needs to express sorrow fully. Listen.	Despair is unbearable. Every day becomes difficult. Simple tasks cannot be done.
Acceptance	**Needed Response**	**Acceptance**
The patient is neither angry nor depressed, only quietly expectant.	Few visitors are required. Quiet comfort. Little talk, presence of cared ones.	Loss becomes reality. Hurt and anger decrease.

The Four Tasks of Mourning—"Grief Work"

Another theory about the grief process is known as the "Tasks of Mourning." Dr. William Worden suggests that each one of us who grieves must accomplish four tasks. Each one of these tasks can be translated into a caregiver's actions.

Task 1: To Accept the Reality of the Loss.

When someone dies, even if it is expected, there is always a feeling that it has not really happened. Therefore, the first task of grieving is to come face-to-face with the reality that the person is dead.

- Caregiver: Talking about the death helps to complete Task 1.

Task 2: To Experience the Pain of Grief.

It is necessary to experience pain in mourning. Anything that suppresses the pain can potentially prolong the mourning process. Society tends to be uncomfortable with mourner's feelings and efforts to comfort often interfere with grieving to the extent that the individual cannot accomplish this important task.

- Caregiver: Grieve, cry, feel the pain of loss. Talk to your friends or coworkers about your pain. This completes Task 2.

Task 3: To Adjust to a New Situation (without the deceased).

Caregivers who lose a patient may feel fearful of their next assignment or of feeling grief in a constant manner. They may withdraw from their patients in anticipation of more loss.

- Caregiver: Begin to establish a positive attitude toward your role in patient care.

Task 4: To Withdraw Emotional Energy and Reinvest it in New Relationships.

This fourth task is to withdraw emotionally from the deceased person so that this emotional energy can be reinvested in life.

- Caregiver: Show caring to new patients who need the same kind of support.

By completing the tasks of mourning the bereaved moves full circle and into a positive approach to continued caring.

What Can You Do To Help Your Patient?

One aim of end of life care is to enable us to die with the same love and caring that is provided for us when we are born. You may be the one to provide that concern, especially if family members can not come to terms with what is happening.

- Instead of feeling sad or distancing yourself from a patient, think of what you can do for your patient, and how your care will ease his or her mind and body. Yes, you will miss your patient, but make the time before death as positive as you can for both of you.
- Draw on your faith. Talk to your patient about theirs if they would like to. Pray together, but do not force your beliefs on your patient.
- Play music. Even Alzheimer's patients often respond to long forgotten, but once familiar tunes.
- Do not take anger personally—from your patient or their family.
- Talk to someone. Find and use support systems. No loss is unshareable.
- Give yourself, and your patient "permission to grieve."
- Just "be there." Dying is a natural event. There are things we can do, ways we can help. These "ways of being" are expressed in terms such as compassion, tolerance, ease, kindness, humor, warmth, wisdom, and stability.
- When caring for a dying person with a background different from yours, never assume that the way you usually speak or respond will work well with that person. Observe how the patient speaks to family members. Ask questions. Not just good, but great care happens when you connect well with your dying client and that person's family. That happens when **you** pay attention to their cultural needs. Pass your insights on to others who share your care giving responsibilities.

What Do You Do When You Discover Your Patient Has Died?

The exact procedure of whom you call and what you do should be discussed with your supervisor ahead of time. You may feel shocked, but you do need to perform the professional part of your job.

It is okay for you to cry, to feel sad, but remember that grief differs based on who we are, whom we have lost, and how much our day-to-day life is altered by the death. You may have feelings of relief, anger, or no feelings at all.

The family, if they are there, may behave in different or unusual manners. They may be shocked, relieved, or angry. They may try to blame someone. They may argue, or try to pull you into their disagreements. Try not to judge, or take their behavior personally. Different cultures and families approach death in different ways.

Feelings

Once the shock has worn off, you may have all kinds of feelings. This is to be expected. Grief is a normal but complex reaction to loss. Let yourself grieve naturally. Do not listen to comments that you are too over-involved, or too jaded and burned out. In time, you will find your own path to deal with patient loss.

Ways to Cope

- Acknowledge your loss. Honor their memory.
- Participate in social customs and rituals. Create a concrete means of remembering or honoring your loved patients—a memorial book or log. If you work in a facility, take part in or hold a memorial service.
- Be proud of your part in comforting your patient.
- Let your feelings rise and flow. Sometimes grief is compared to the ocean, where waves rise and fall, then recede, and come back.
- Share your feelings. Join a grief group if you can. Talk to co-workers, or your supervisor.
- Be comforted by offering comfort.

Words of Inspiration

Mother Theresa's Golden Rules

People are often unreasonable, illogical and self-centered;
Forgive them anyway

If you are kind, people may accuse you of selfish, ulterior motives;
Be kind anyway.

If you are successful, you will win some false friends and some true enemies;
Succeed anyway.

If you are honest and frank, people may cheat you;
Be honest anyway.

When you spend years building, someone could destroy it overnight;
Build anyway.

The good you do today, people will often forget tomorrow;
Do good anyway.

Give the world the best you have, and it may never be enough;
Give the world your best anyway.

You see in the final analysis, it is between you and God;
It was never between you and them anyway.

My religion is kindness.
— *His Holiness the Dalai Lama*

Using Faith

Faith, above all, gives comfort to the dying and the bereaved.

It is important to have a healthy spiritual approach to death and dying. Dying patients need and deserve understanding spiritual support. Those who are dying, for the most part, want to talk about their death and spiritual beliefs. It is important to value and understand the importance of this to your patient, even if your beliefs are not the same. If your faith is the same, give support. If it is not, listen, ask questions. Do not support a patient's attitude that God is to blame, or make them feel guilty. Try to understand what the patient is dealing with as they confront their death.

Take this approach in developing a healthy understanding of death and dying:

- God does not cause bad things to happen;
- God does not single us out for tragedy as a form of punishment;
- Natural laws are at work in the world;
- Any one of us can get coronary artery disease, cancer, and any number of other diseases;
- God allows it to happen but does not cause it to happen; and
- Death is as natural as birth.

A simple prayer may help **"Be strong and of good courage; do not be afraid, nor be dismayed, for the Lord your God is with you wherever you go**" (Joshua 1:9).

You need to be honest with your patient, and perhaps with yourself, and say you do not understand everything that happens to people, or what is and is not God's will.

As you help your patients go through the painful days prior to their death, or as you cope with the loss of a favorite patient, you may struggle with your own faith, and question God. You may blame God, or question God's caring. It is important to seek help to work through this time. Questioning faith is a normal reaction to loss. Talk to your minister, your priest, or spiritual counselor to resolve your questions and fears. If you are part of a hospice team, draw on their support.

Saying Good-bye

There comes a time to say good-bye. Letting go is one of the most powerful expressions of faith and greatest parting gifts you can offer your dying loved one. Comforting words of letting go allow you to give up control (and many hours of caregiving), trusting instead in God's love. Your words and your assurance also offer your patient the comfort of knowing that you trust in God.

Miss Me, But Let Me Go

Miss Me, But Let Me Go
When I come to the end of the road
And the sun has set for me
I want no rites in a gloom filled room
Why cry for a soul set free

Miss me a little-but not too long
And not with your head bowed low
Remember the love we once shared
Miss Me, But Let Me Go

For this is a journey that we all must take
And each must go alone
It's all part of the Master's plan
A step on the road home
When
you are lonely and sick at heart
Go to the friends we know
And bury your sorrow in doing good deeds
Miss Me, But Let Me Go

Questions of Reflection

As you think about your patient, remember how important you were to him, and the value of your caring. It is a true gift.

Who was your patient?

> He was a person who asked about my family everyday. He was a war veteran with amazing stories. She was a person who cared about everyone. Why was this person special? What qualities, good or bad, did they have?

What did you do for them?

> I gave him a bath and made lunch. I listened when she talked about her grandchildren and the husband she lost a few years before. I was with him at Christmas when his son didn't bother to visit. What did I mean to my patient? What did he or she mean to me?

Why now?

> He was working so hard to recover from his stroke. She was looking so forward to her daughter's visit. Why does death happen when there is still life to live? Why does death not always feel fair?

Where do they fit in my life?

> This was not a parent, sibling, neighbor, or friend. I was paid to take care of this person. Why do I feel so sad?

When does this get better?

> Sometimes when I lose a patient it hurts. Other times it does not seem to hurt as much. Why does the death of some patients hurt more than others? When will I be able to handle the fact that my patients die?

How can I keep doing this?

> There are just some days that I do not want to come to work anymore. I just feel like I can not handle one more person dying. Then there are days I make a patient smile or someone tells me thank you. Those are the days I cannot imagine doing anything else. How can I have more of those days than the bad ones?

Summary

In order to maintain a positive attitude about the valuable care and support they provide dying patients, caregivers need to understand both their own grief, and that of their patients.

Grief is a natural healing response to a loss and must be dealt with in a healthy manner. Mourners go through phases—tasks or steps—as they gradually recover from their loss. Recovery is slow, with many ups and downs as warm remembrances, acceptance of loss, and new emotional attachments gradually replace painful feelings. Faith and spiritual beliefs are a valuable comfort both to dying patients, their families, and caregivers during time of loss.

Coping Strategies

- Let yourself grieve positively, knowing you were of comfort to your patient and made a difference in their life.
- Recognize the feelings for what they are, not why they are.
- Value yourself. Take care of yourself, rest, exercise, read, sing, dance, pray. Do whatever it is that gives you peace.
- Use humor to relax the stress and bring balance to your life.
- Change the things you can; accept the things you cannot.
- Seek help, support, and friendship; talk to others who have shared the same experience. Speak of the meaning of the loss to you.
- Nurture your spiritual sense. Seek guidance from those who can offer you both wisdom and comfort.

And most importantly, be comforted by offering comfort.

Notes

Name_____

Quiz

1. Grief is:
   (a) A natural process.
   (b) A normal reaction.
   (c) A time of healing.
   (d) All of the above.

2. Bereavement is:
   (a) The adjustment period following the loss of a loved one.
   (b) The period of time before the loss of a loved one.
   (c) A time when a caregiver should ignore the patient.
   (d) None of the above.

3. Coping Strategies for dealing with patient loss include:
   (a) Acknowledging the loss and resulting feelings.
   (b) Sharing feelings.
   (c) Using faith, humor, and support.
   (d) All of the above.

4. Caregivers who do not grieve patient loss might:
   (a) Protect themselves by becoming numb.
   (b) Leave the field to avoid feeling the pain of patient loss.
   (c) Become jaded and hard.
   (d) All of the above.

5. Faith and spiritual beliefs can be:
   (a) A source of comfort to the dying and their family.
   (b) A source of comfort to the caregiver.
   (c) Confusing to those seeking to find comfort by understanding death.
   (d) All of the above.

6. The Stages of Grief are:
   a) Phases mourners move through as they heal from their loss.
   b) Stages mourners use as part of a funeral service.
   c) Stages dying patients go through as they cope with approaching death.
   d) Both (a) and (c).

True or False:

7. ____The Tasks of Mourning are: Accepting, Feeling, Adjusting, and Reinvesting.

8. _____When you discover that a patient that you care for has died, you should follow the procedures taught by your agency.

9. _____Reactions to patient loss vary according to a person's culture, gender, past experience with death and closeness to the patient.

10. ____ Anticipatory or pre-grief occurs before patient death.

11. ____Hospice is a concept of providing quality, palliative care to the terminally ill and their families.

12. ____Palliative care means making the patient as comfortable as possible but not trying to cure him/her.