A NATIONAL EPIDEMIC

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Introduction

Death is all around us – everywhere we look. Death is the most certain aspect of life. Eventually death touches each of us. At one point in time, dying and death will become a personal, intimate experience because we are all destined to die.

Our feelings and our beliefs about death dictate, largely, how we live our lives. Identification and examination of these feelings, attitudes, beliefs and values lead us to greater insight and understanding when we face a situation in which someone is dying.

Because nurses are frequently involved in situations associated with dying or prolongation of life, it is mandatory that we reflect on our feelings, attitudes, beliefs and values about living and dying.

This program is designed for nurses who are frequently confronted with people who are facing death. This includes all of us, whether we are engaged in active clinical practice or are simply involved in the activities of daily living.

The purpose of this program is to provide basic information that will be helpful in dealing with people who are facing death or the loss of a person they love. The program is written from a Biblical Christian perspective because it is rarely dealt with in a straightforward manner in the professional literature and because this author believes Christ is the only true source of hope for anyone facing death.

Defining Death

Death represents the inescapable end of every human life, for in the created order of nature all living organisms decay and perish with time. Man becomes inevitably involved in dying from the moment of conception.

Death has been a mystery to man since his beginning. It has always been a topic that has raised many questions – questions that are not easily answered: What is death? What happens at the moment of death? What happens to a person’s soul or spirit? Is there life after death?

Defining death has become increasingly difficult because of legal and technical problems. The determination of the moment of death is a question with vast societal and moral implications in this age of transplants and fantastic life-sustaining machines.

Death is not an instantaneous event; rather, it is a process, the initial phases of which are sometimes reversible. The following are some of the terms used to define death:

Somatic - cessation of all vital functions, such as heartbeat and respirations.
Cardiac - cessation of heartbeat, verified by electrocardiogram.
Brain - unreceptivity, unresponsiveness – no movements or breathing, no reflexes and a flat electroencephalogram.

Clinical - appearance of death signs on physical examination before technical pronouncement of death.

Biological - cessation of all cellular activity.

A Biblical definition of death is the separation of body and spirit. The Bible says, “The body without the spirit is dead...” (JAMES 2:26)

Death and the definition of death are subjective in nature. There are many facts that are known about death, but some aspects of death remain a mystery. It is important for us to realize that every person will view and define death differently and we need to respect those differences even when we do not agree with them.

Cultural And Societal Changes

In 1900, 53 percent of all deaths recorded in the United States were of children under the age of 15. The average lifespan at that time was 47 years. Today a Caucasian male can expect to live more than 74 years and a Caucasian female 79 years. People are living longer; as a result, death most often occurs in old age.

Along with the increase in lifespan has come a change in the causes of death. As you can see in Figure 1 on the following page, many of the illnesses that are causing death today are degenerative lingering illnesses. In this age of rapid medical and technological advances, even heart diseases have become chronic illnesses. Because many illnesses are chronic and debilitating, there are often major lifestyle changes that can be stressful for the ill person and his family. The longer the process of dying is, the greater the emotional, physical and financial stresses that confront the individual and his family.

It is a well known fact that most people in the United States today die in institutions rather than at home. In 1900, people died at home surrounded by family and friends. Today people die in depersonalizing institutions that are not set up to meet the human needs of people who require palliative care.

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Attitudes Toward Death

Before discussing how attitudes toward dying and death are developed, take a few minutes to do the following exercise:

Collect a piece of paper and a few colored pencils or crayons.

1. Draw a picture of what death looks like or of what death means to you.
2. Now, on that same paper, write down a few words or phrases that describe how you feel about death. Do not spend a lot of time thinking about it, just those words that first come to mind.
3. Finally, turn the paper over and write out your definition of death.

Answer the following questions about the above exercise:

1. What color is predominant in your drawing? Is it a dark color or a bright color?
2. What significance does your picture have? Is it a significant event in your life or is it your concept of death and what you anticipate death to be like?
3. Did you use optimistic or pessimistic words to describe how you view death? How does thinking about death make you feel?

4. In general, what is your attitude toward death?
   
   Our understanding of death develops as we mature. In an early study done by Maria Nagy (1948), Nagy showed that a child’s awareness of mortality develops in three phases:
   
   1. The child who is less than five years of age does not recognize death as an irreversible fact; therefore, death is seen as a temporary situation. Life continues only under changed circumstances. Children believe the deceased eat, breathe, think and feel only in the confines of a coffin.
   2. Between the ages of 5 and 9 years, the child appears to be able to accept the idea that a person has died but may not understand that it is something that happens to everyone and particularly to himself. He sees death as a person; someone who takes human form, visits those about to die and takes them away.
   3. Around the age of 9 or 10, children recognize that death is irreversible and universal. The child realizes that death is a process that happens according to certain laws. It is important to realize that a child’s perception of death is dependent upon his stage of development more than his age; however, for the majority of children, age and development occur simultaneously. What children know and tell you about death reflects their experience, concerns, circumstances and self-concept.

   Studies done related to college-age students and their attitudes toward death appear to be inconsistent. Some studies indicate that college students show little concern with death; while other studies suggest that students are concerned with death but subconsciously suppress their real attitudes toward it.

   Research related to death attitudes in adults is minimal. Past experience, family attitudes, religious beliefs, education, maturity and other factors influence adult’s attitudes towards death.

   Adult’s attitudes toward death continue to change as we live and experience life.

   In America, people have moved away from the old traditional view of death. America’s current attitude toward death is deeply ambivalent: awe of death and an attraction to death; risking death and loving life; wanting happiness and behaving in self-destructive ways; regarding death as taboo and insisting on a new permissiveness to talk about it; and an obsession with terrorism and a deep concern about spiritual rebirth.

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**Table 1:**

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause of Death</th>
<th>Rate (per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Influenza, Pneumonia</td>
<td>202.2</td>
</tr>
<tr>
<td>2</td>
<td>Tuberculosis</td>
<td>194.4</td>
</tr>
<tr>
<td>3</td>
<td>Gastroenteritis</td>
<td>142.7</td>
</tr>
<tr>
<td>4</td>
<td>Heart Disease</td>
<td>137.4</td>
</tr>
<tr>
<td>5</td>
<td>Strokes</td>
<td>106.9</td>
</tr>
<tr>
<td>6</td>
<td>Chronic Nephritis</td>
<td>81.0</td>
</tr>
<tr>
<td>7</td>
<td>Accidents</td>
<td>72.3</td>
</tr>
<tr>
<td>8</td>
<td>Cancer</td>
<td>64.0</td>
</tr>
</tbody>
</table>

*Source: 1900-1940 tables ranked in National Office of Vital Statistics, December 1947*

**Table 2:**

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause of Death</th>
<th>Rate (per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Disease of Heart</td>
<td>191.4</td>
</tr>
<tr>
<td>2</td>
<td>Malignant Neoplasms (cancer)</td>
<td>184.6</td>
</tr>
<tr>
<td>3</td>
<td>Chronic Lower Respiratory Diseases</td>
<td>46.0</td>
</tr>
<tr>
<td>4</td>
<td>Cerebrovascular Diseases</td>
<td>41.4</td>
</tr>
<tr>
<td>5</td>
<td>Accidents (unintentional injuries)</td>
<td>39.4</td>
</tr>
<tr>
<td>6</td>
<td>Alzheimer’s Disease</td>
<td>27.2</td>
</tr>
<tr>
<td>7</td>
<td>Diabetes Mellitus</td>
<td>23.5</td>
</tr>
<tr>
<td>8</td>
<td>Influenza, Pneumonia</td>
<td>17.2</td>
</tr>
</tbody>
</table>

*Source: National Vital Statistics, NVSR, Volume 61 #6, October 10, 2012*
Views of death have undergone radical changes in the last few generations. Twentieth century people have made themselves the center of their own universe. Secular humanism and existentialism are the predominant philosophies adhered to in America today and these philosophies have had a strong influence on forming death attitudes in this secular age. These philosophies purport that death is the end, that there is nothing beyond this life.

Universal Fear Of Death

While man’s view and attitude toward death may be changing in philosophical ways, his fear of death and the unknown remain ever present. Ernest Becker in his book The Denial of Death states: “The idea of death, the fear of it, haunts the human animal like nothing else; it is a mainspring of human activity – activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny for man.”

For most people any confrontation with death is dreaded and often avoided. The fear of death is universal. The fear of death is not merely a cultural phenomenon but a part of being human. The unknown aspects of death, the termination of the experiences of living and the conclusion of all the controllable activities of life all create a pervading dread of death.

Death is a paradox – it is both a destructive and a creative force. The basic premise of this paradox is that human beings are fearful and anxious about death and yet it is the same fear that directly or indirectly motivates much of our behavior and how we live our lives. A healthy fear of death protects us against death; i.e., we do not take unnecessary risks or chances that put our lives in jeopardy. Therefore, the thing we fear is that which helps us to stay alive.

The Denial Of Death

Man cannot conceive of himself in a state of nonexistence, for to do so goes against everything in his experience. Yet, he knows that death will be an inevitable outcome. Because of the tension created within him, man erects defenses to deal with his anxiety.

The societal tendency is to avoid and repress any contact with death. We deny death by becoming youth-oriented, future-oriented, by institutionalizing people who are severely or terminally ill or dying. The dying person is not seen as an individual but as a symbol of what every human fears. Our denial attitude is evident in the euphemistic tendency to label the end of life as anything but death; i.e., “passed away,” “passed on,” “expired,” etc.

No matter how hard we try to hide from the knowledge of our finite existence, we will never succeed. Our relationship to the world, to time and to others is bound in a sense of inevitable death. To learn not to be so afraid of death is an important step in learning how to live.

The Meaning Of Life

Death and life are intimately related. In many ways, they are impossible to separate. Death confronts us at every turn of life.

Therefore, as we struggle to find meaning in death, we need to also struggle and look at the meaning and purpose of life.

Take a few minutes to think seriously about the following questions:

1. Who am I?
2. What am I doing here?
3. Why am I here?
4. What purpose does my life have?
5. What meaning does my life have at this time?
6. Of what value will my life have been when it is all over?
7. Did my being here make any difference?

Do you ever ask yourself these questions? In light of the philosophies of secular humanism and existentialism, it would seem these questions would lead one to despair. If this is all there is to life – if there is nothing beyond this earthly life – then the beer commercials are right: “You only go around once in life, so grab all the gusto you can get.”

In reviewing the literature about death, it is interesting to observe that there is little that speaks to the meaning and value of life. Is it any wonder that we live in what has been termed the “age of melancholy”?

What then is life? Where do we find meaning and purpose for our lives and for living? Is it only in the face of death that we find the true meaning and value of life?

The Bible offers answers to these questions. Christianity, in the Biblical sense, gives meaning and purpose to life. The tenets of Christianity include value, purpose and hope for human life.

The value God placed on life is evident from the beginning because God created life and saw that life was valuable and worthwhile.

“And the Lord God formed man from the dust of the ground and breathed into his nostrils the breath of life and man became a living being. God saw all that He made and it was very good.” (GENESIS 1:31, 2:7)

God loved His creation and had regular and intimate fellowship with man from the very beginning. However, man chose to disobey God and, as a result, severed that close relationship with God. (GENESIS 3)

However, it was God’s desire to restore that broken relationship with man. He placed such a high value on the relationship that He sent Jesus Christ to earth in the form of a man. (MATTHEW 1:21) However, in order to restore man to his rightful relationship with God there had to be a sacrifice made. Jesus Christ became that Sacrifice. Christ gave up His life that we might be reconciled to God and live in fellowship with Him.

“But God demonstrated His own love for us in this: While we were still sinners Christ died for us.” (ROMANS 5:8)

Because of the death of Jesus Christ, we are spared God’s wrath and judgment toward our disobedience and self-centeredness:

“The wrath of God is coming from heaven against all the godlessness and wickedness of men who suppress the truth by their wickedness.” (ROMANS 1:18)

“Since we have now been justified by His blood, how much more shall we be saved from God’s wrath through Him? For if, when we were God’s enemies, we were reconciled to Him through the death of His Son, how much more, having been reconciled, shall we be saved through His life!” (ROMANS 5:9-10)

Because of the resurrection of Jesus Christ, we have the opportunity given to us to have life and have fellowship with God forever.

“For God loved the world so much that He gave His only Son, that whoever believes in Him may have eternal life. God demonstrates His love for us in this: While we were still sinners Christ died for us.” (ROMANS 5:8)

How does this relate to finding meaning and purpose in life for us today?

1. Human life is valuable; God says that it is. God demonstrated just how valuable by sacrificing His Son.
2. My life does have meaning. That meaning comes because my relationship to God has been restored and it is my desire to please Him.
3. The purpose of my life is to praise and worship a worthy God.
4. This life is just one phase of my life, which is eternal – from everlasting to everlasting.

Following as a disciple of Christ offers meaning and purpose for this life and the hope of life and fellowship forever with God.
The Meaning Of Death

We have examined the meaning of life from a Biblical, Christian perspective, what about the meaning and purpose of death? What does the Bible say about death?

There are at least four factors that offer some reason or purpose for death:

1. Death came about because of man’s disobedience toward God. All men will die because all have sinned: “Therefore just as sin entered the world through one man and death through sin, and in this way death came to all men, because all have sinned.” (ROMANS 5:12) “There is no difference, for all have sinned and fallen short of the glory of God and are justified freely by His grace through the redemption that came by Christ Jesus.” (ROMANS 3:23-24)

2. Death makes us appreciate life and living. It helps us to appreciate the relationships we have with others and the essence of life. Death makes us aware that we truly have only today. “So teach us to number our days that we may get a heart of wisdom.” (PSALMS 90:12) “Why, you don’t even know what will happen tomorrow. What is your life? You are a mist that appears for a little while and then vanishes. Instead you ought to say, ‘If it is the Lord’s will, we will live and do this or that.’” (JAMES 4:14-15)

3. Death brings relief from suffering: “For while we are in this tent (body) we groan and are burdened, because we do not wish to be unclothed but to be clothed with our heavenly dwelling, so that what is mortal may be swallowed up by life.” (2 CORINTHIANS 5:4)

4. Death allows us to realize eternal life with Christ. Although eternal life begins when we accept Jesus Christ as our personal Savior, we do not know the reality of that intimate fellowship with God until we die: “I write these things to you who believe in the name of the Son of God so that you may know that you have eternal life.” (I JOHN 5:13) These are purposes that can be found in death; however, death was not intended by God to be a part of life. Death has never been a friend to man and never will be: “The last enemy to be destroyed is death.” (I CORINTHIANS 15:26) However, because of the life and death of Jesus Christ, we have victory over death.

“The sting of death is sin and the power of sin is the law. But thanks be to God! He gives us the victory through our Lord Jesus Christ.” (I CORINTHIANS 15:56-57)

Immortality

According to Christian beliefs, our souls are immortal and will live forever. All men will live forever, some in fellowship with God and some condemned to eternal punishment or separation from God: “Do not be amazed at this, for a time is coming when all who are in their graves will hear His voice and come out — those who have done good will rise to live and those who have done evil will rise to be condemned.” (JOHN 5:28-29)

All men desire and search for immortality. Five different modes of immortality have been expressed:

1. The biological mode is the sense of living on through and in one’s children and grandchildren. This develops strong family and blood ties.

2. The mode of creativity is the sense of living on through one’s works, such as writing, painting, teaching and human influence. The idea is that one’s contributions will not die.

3. The mode of eternal nature is the sense of immortality achieved through being survived by nature.

4. The mode of experiential transcendence is a state in which the psychic state achieves ecstasy or rapture. It is at this point of ecstasy that the restrictions of the senses no longer exist, including the sense of mortality.

5. The theological mode is the sense that there is life after death. That man is able to transcend death. All religions have some method of transcending physical death.

These modes of immortality are all interesting to ponder; however, in this age of nuclear power, all modes except the theological mode could and would be destroyed by one well placed bomb. Our hope for the future, in both this life and the next, rests with a belief in the grace of God through Jesus Christ.

At this point, take some time and write down your philosophy and beliefs about life and death.

Now that we have laid some foundations for this issue of death, let us examine what happens to people in the actual situation and how we, as nurses, can intervene.

Fears Of The Dying

For many people, if not most, fears associated with dying are often greater and more pressing than the fear of death itself. We need only to think of dying and what it would be like to realize some of the fears associated with the dying process.

The following is a list of the most common fears associated with dying:

1. Fear of helplessness, loss of control over one’s own life
2. Fear of being alone, deserted, isolated, abandoned
3. Fear of being dead, of non-existence
4. Fear of pain and suffering
5. Fear of being a burden
6. Fear of humiliation: loss of bodily functions, bowel and bladder control; loss of hair, etc.
7. Fear of separation from loved ones
8. Fear of the future for loved ones left behind
9. Fear of punishment
10. Fear of impairment, of being unable to care for self
11. Fear of the unknown
12. Fear of what will happen to projects already started, of inability to achieve goals
13. Fears associated with finances
14. Fear of the loss of emotional control

These fears and uncertainties are completely understandable. The threat of death produces many fears and raises a host of questions for the immediate future. How long do I have? How will I provide for my family? Can I keep on doing my job? How quickly will I deteriorate? Who will care for my family after I am gone?

There are no easy answers or solutions to allay these fears, but it is important that an atmosphere of warmth and acceptance be provided so that these fears can be explored and, when possible, solutions found to reduce some of these fears.

Emotional Responses To Dying

While these fears are common to all, individuals have different ways of dealing with them. It is important for nurses to realize these differences. Dr. Elizabeth Kubler-Ross has identified five stages, or emotional responses, that people may experience when they become aware that they are dying: denial, anger, bargaining, depression and acceptance.

Let us examine these five emotional responses and how, as nurses, we can intervene.

Denial

Denial is as any behavior that allows a person to avoid facing reality, to evade a painful situation or to escape confronting anything unpleasant. The typical response most people have to receiving news of a terminal illness
is disbelief, that there must be some mistake. This state is often called the “No, not me, it can’t be true” state.

Denial is usually a healthy response. It acts as a buffer when receiving unexpected, shocking news. It provides the individual with the time necessary for him to collect his thoughts and to mobilize other defense mechanisms that can help him cope with the situation.

Denial takes many forms. It may involve failing to hear or understand his diagnosis. Sometimes it is talking of a completely unrelated reason for being sick and in the hospital:

“The doctor says I have a tumor in my bowel, but I’m sure my problem is this hernia. If he would fix it, I would be fine.”

Denial may take the form of focusing on unrealistic plans for the future — for instance, “When I get well.” Sometimes an admission to the hospital is interpreted as a sign of health rather than a serious illness:

“They brought me into the hospital because they caught it early.”

Occasionally, denial becomes unhealthy and can be destructive. This may be seen in the person who refuses to accept the truth and goes “shopping” for a doctor who will tell him what he wants to hear. If a person refuses treatment or refuses to comply with prescribed medication or diet because he “isn’t sick,” the result could be fatal.

The dying person may use denial selectively. He may adopt denial behavior with some people and talk openly with others about the seriousness of his situation. For example: denial behavior may be used with doctors and nurses if the patient perceives them as demanding his recovery or he may use denial with family members if he is afraid they won’t be able to handle the truth.

No one is capable of continuously facing the fact that he is dying. Therefore, denial is necessary for every patient at times. There are times when he will want to talk honestly about his situation and then there will be times when he will need to look at brighter, more cheerful things in life. Throughout his illness, the need to use denial will come and go.

What are the needs of the person who is denying death? He needs time and patience from those around him. He needs people to be sensitive listeners who will be gently honest with him as he sorts through his feelings about his situation. There will be times when he will need to be reminded of the facts and to be given further information about his diagnosis and illness. It is important to provide information about his illness, as he is ready for it. He will not be able to hear it all at one time. He will ask for information, as he is ready for it.

Individuals usually give us clues when they are ready to talk about death and dying.

If we ignore these clues, then we reinforce their denial and engage with them in their game of pretense.

People also become aware of whether or not we are willing to talk about death with them by the verbal and nonverbal clues we give them. If a nurse walks into a room and takes care of business but does not engage in any meaningful conversation with or even look at a patient, the patient will get the idea that the nurse is not interested or able to talk with him about his situation. However, if the nurse is willing to ask a few simple leading questions and take some time with that person, he will know that the nurse is willing and ready to talk whenever he is ready.

Being available, listening and being willing to talk honestly with a person who is in the state of denial is the most important means of intervention for the nurse.

**Anger**

Fears and anxieties develop within the dying person, as the threat of death becomes more clearly understood. For most of us, it is difficult to admit we are afraid and, as a result, the fear is expressed as envy, bitterness and anger. The logical questions are “Why me? What did I do to deserve this?” Because the unfairness of it all is overwhelming, the person lashes out.

In contrast to the denial response, anger is a difficult response for both the dying person and for those around him. The anger is displaced in all directions and projected onto the environment and whoever happens to be available. The doctors are “no good – they don’t know what they are doing.” The food is “cold and tastes awful.” The roommate is “too sick” or “too noisy.” The nurses are “never available” when they are needed. When they are available, they “never leave him alone.” The family does not do anything “right” either. They either “come too early” or “should have come sooner.” They “stay too long” or “not long enough.” Even the television has the “wrong type of programs!”

Often the real problem of anger stems from the fear of being alone and forgotten. So this person makes sure he is not forgotten by raising his voice, making demands and asking for attention. He may be saying: “I am alive, don’t forget that. You can hear my voice, I’m not dead yet!”

A person who is respected and understood, who is given attention and some time, will soon lower his voice. He needs to be listened to and cared for. Sometimes his complaints are valid; something needs to be changed or corrected. Therefore, it is important to really listen to what he is saying.

Another reason people get angry about their illness is because they feel they have lost control of their life and what is left of it. Angry demands may be expressions of the need to find ways to regain at least some control over life. All too often decisions are made for the terminally ill person and not with him. Families and physicians decide if the person should be told his diagnosis and how much he should know.

Physicians often choose the method of treatment, if any, rather than inform the patient and his family and let them make the decision. Most people get angry when these controls are taken from them.

Flashes of anger and attacking behavior may be embarrassing to the person who is ill. He needs time, understanding and patience. Anger and temper tantrums may produce guilt within the ill individual. We need to be ready to offer forgiveness and love when asked.

Often the anger of the ill person will alienate those of us around him. We take complaints and remarks personally and retaliate in anger and defensiveness. We need to understand that the anger is not directed at us personally. We should listen with acceptance and not condemnation, not pull away, or strike out at him in reprisal. We should correct those things that need to be changed, help him realize that there are things he can still control in his life, then allow him that control whenever possible.

There are times when anger is hidden and not faced. Our culture cautions us that something is wrong with expressing anger, that we really should not express it. For the Christian, anger is doubly taboo, for it is frowned on by society and totally forbidden by the church: “Good Christians don’t feel, express or deal with anger.” As a result, people repress their angry thoughts and feelings and instead focus on their hopelessness, worthlessness and helplessness.

Unresolved anger can lead to depression, feelings of guilt and a sense of hopelessness and despair. In its extreme form, these feelings may need professional intervention to prevent suicide, either by active or passive means, such as inadequate intake of food or fluids.

One issue related to anger rarely dealt with in the literature is anger toward God. How often have you heard someone ask: “What did I do to deserve this?” “I’m not a bad person – why is God punishing me.”

For the most part, people tend to view God as all-loving and all-caring. The image that comes to mind is that of a “Celestial Grandfather” who desires to give us only good things. That
image holds true until something bad happens to us. Then, suddenly, God is blamed for not being “big enough” to prevent it; He becomes a “Celestial Scrooge” — out to get us. How often have you heard someone say: “If God is so powerful, couldn’t He prevent this from happening to me?”

God is all loving and caring. He loved us enough to send His Son to die for us. God has many other attributes as well. God is just, righteous and holy.

Our understanding of the power and majesty of God has somehow been distorted to the point that man tries to make God according to man’s own image and desire; he resists being conformed to God’s image and decrees.

Secondly, it is important to realize that we are not puppets on a string. God has given us freedom of choice and free will. We choose how we live and often it is our life style that causes illness. Things happen in this world because God has given man free will. What would we think if God started taking things away from us because

He knows what is best for us and knows that would prevent bad things from happening? Where would He draw the line?

Surely, we would be angry with Him if He took too many of our freedoms away.

Thirdly, disease came into the world because of man’s disobedience to God. Sickness and death are part of being mortal and finite. They will be part of life until the last enemy is destroyed and the mortal becomes immortal – that is, until Christ returns.

God cares about us and is interested in everything that happens in our lives. I do not believe that God expects us to accept our difficult situations automatically and without question. God understands what it is to be human. Not only did He create us, He came to earth in the form of a man and lived in human form for 33 years. The Bible tells us that Christ was tempted in every way that we are and yet He did not sin:

“For we do not have a high priest who is unable to sympathize with our weaknesses, but we have one who has been tempted in every way, just as we are – yet without sin.” (HEBREWS 4:15)

God knows and understands our heartaches and our grief. I believe He also understands our anger – even our anger toward Him. The best way to deal with our anger toward God is to be honest with Him about it. By allowing our doubts and questions to be expressed to God, we learn that He is big enough to handle the hard issues of life and death, that He can give meaningful, satisfying answers. We cannot be like an angry child, however and expect God to force Himself on us. Have you ever tried to embrace an angry child? The love you try to express meets the barrier of the child’s anger – stiff shoulders, head turned aside, muscles struggling and writhing to get away – and often refusal to listen or be reasoned with. In that situation, there is nothing you can do until the child cools off and his anger subsides.

Hidden anger puts a barrier between the angry person and God. It must be confessed and dealt with so God is able to comfort us and reassure us of His presence even in the most difficult times. His promise is to never leave or forsake us:

“Fear not, for I have redeemed you; I have called you by name; you are mine. When you pass through the water, I will be with you; and when you pass through the rivers, they will not sweep over you. When you walk through the fire, you will not be burned; the flames will not set you ablaze. For I am the Lord, your God, the Holy One of Israel, your Savior . . .”

(ISAIAH 43:1-3)

This is God’s promise to all those who believe He is the one true God and who live by faith in His promises.

Bargaining

This is the stage where the person enters into some kind of agreement, which may postpone the inevitable happening. The terminally ill person asks for favors on conditional promises. Most bargains are made with God and are usually kept secret or mentioned between the lines: “If God lets me live, I’ll go to church every Sunday.” or “I just want to see Bobby graduate from high school.”

Psychologically, these promises may be associated with guilt and it is important that these remarks not be brushed aside by staff. It is possible that the person does feel guilty for not attending church more regularly or because he feels as if he is abandoning Bobby. It may be helpful to consult a chaplain or a psychologist if the terminally ill person has guilt that needs to be dealt with before his death.

Bargaining may also be important in allowing that person to maintain some hope. Bargaining is a way of fixing hope, of saying that in spite of the fact that he is dying there is still something to live for. Often that individual lives to see Bobby graduate.

There are times when bargains become unrealistic and it is necessary for us to help that person be honest in his expectations and to help him clarify realistic alternatives. It is important to help him maintain hope without being unrealistic in his expectations.

Depression

Depression comes when the terminally ill person can no longer deny his illness. His symptoms have progressed and he has become progressively weaker. The dying person has had to face many losses. His illness has created financial burdens: he has lost his job or at least has not been able to work. There have been role changes within the family structure and he has become dependent on others to meet his physical needs. Often his body image has changed due to surgery, weight loss or therapy. In general, he feels a loss of self-worth and self-esteem. This type of depression is reactive depression.

A dying person suffering from reactive depression should be encouraged to verbalize his concern about his losses. An understanding person will have no difficulty in eliciting the cause of the depression and in alleviating some of the unrealistic guilt that accompanies it. For example, a woman who is worried about no longer being a woman after a mastectomy, could be complimented on some especially feminine feature. Breast prosthesis could be helpful in helping her view herself as feminine in appearance. It may be important for a woman to know that her children will be well cared for after her death and that they can be happy.

Reactive depression is often lifted when the issues contributing to the depression are resolved. This is when it is important for the nurse to call upon other members of the health care team to assist the dying person in meeting these needs. Social workers, chaplains and organizations such as Reach for Recovery can be particularly helpful.

Another type of depression that the terminally ill person may experience is preparatory depression. This type of depression comes as the dying person prepares himself for his final separation from this world and everything that he knows and loves.

It does not occur because of past losses but takes into account impending losses. Preparatory depression is often silent; the person seems withdrawn. There is no need for words. Often the presence of people who care and their physical touch is more important than words. This is the time when the dying person may just ask for prayer, when he begins to occupy himself with things ahead rather than behind. It is a time when too much interference from visitors who try to cheer him up is a hindrance to his emotional preparation for accepting his own death. He needs the freedom to express his sorrow.
It is important for the nurse to be available to a person suffering preparatory depression, particularly if she has established a meaningful relationship with him. Her presence and touch are important, as is an attitude that allows the dying person to grieve over his losses. If the nurse is comfortable in sharing appropriate passages from Scripture and praying with the dying person, she may provide a great deal of comfort. If the nurse is not comfortable sharing spiritually with the patient, then it is important to find another resource person, such as a chaplain, who can meet the need and offer reassurance.

Acceptance

If the person has had enough time and has been given some help in working through the previously described stages, he will reach a state of acceptance. Usually, during this time there are no strong feelings, but rather a sense of calm readiness to die. It is at this point that he may withdraw from most relationships and select only a few important people with whom to relate. The communication desired by him is often non-verbal instead of verbal. Touch and the presence of those he has chosen to be with him are more important than news from outside.

This is a time when the family needs more help, understanding and support. They may not be ready to accept his death or understand why he is withdrawing from them. The terminal setting can be more disruptive and frustrating for those who live than for the person who dies. Many families find themselves torn apart, both physically and emotionally, by their confrontation with death.

It is important for us not to view these “stages” as a necessary sequence of reactions, which every person must go through for a “normal” terminal illness. Some people will go through the phases of reaction quickly or they may go through them silently. They may skip stages or vacillate from one stage to another. Personality and personal resources will affect how a person responds to the fact he is dying.

These stages are not presented for us to diagnose or categorize people we care for. It is simply that we need to realize that certain reactions are normal, to be expected and that we can accept these reactions and continue to affirm the person. If we have some idea of what to expect and some idea of how to respond, we will be more effective in our intervention and care of those who are dying.

The Family’s Response To Dying

We cannot help the terminally ill person in a meaningful way if we do not include his family. The family plays a significant role during the time of his illness and their reaction will contribute to how the patient responds to his illness.

Serious illness and hospitalization bring about many relevant changes within the family structure. In the case of the terminally ill husband, the wife faces the loss of security and dependence on him. She has to assume responsibility for financial and business matters for the family, and it may necessitate her getting a job outside the home. If hospital visits are involved, she will need to take time from an already demanding schedule. There may be subtle or dramatic changes in the household and in the atmosphere at home, to which the children will also react. Their role within the family may change with the increased expectations and demands made on them. Children may suddenly be expected to respond and act like adults and assume adult roles within the family and home. On the other hand, children may be kept isolated from what is happening to their parent; they may feel abandoned and alone.

The husband whose wife is terminally ill will also sense great loss. He suddenly has to be concerned about meals, laundry, the children’s schedule and other concerns that his wife previously took care of. He may have to serve instead of being served. Instead of being able to rest after a day at work, he will have other responsibilities to care for at home.

Just as the terminally ill person goes through various stages or emotional responses to dying, so do family members. Dr. Kubler-Ross believes that the family members go through the same five stages that the patient goes through when facing death (denial, anger, bargaining, depression and acceptance). Other authors have identified other responses. In doing the research for this book, I have identified six phases that families experience as they face the loss of one they love.

Denial

Because of our “belief” that bad things always happen to someone else, family members generally react by denying the seriousness of the situation. This time of denial helps them maintain some sense of stability and security until they have time to mobilize the emotional defenses necessary to help them cope with the reality of the situation.

Denial may also be used for a time for the good and encouragement of the dying person. It allows everyone some time to let the facts of the situation sink in so they can deal with them more effectively and realistically.

Living with the Diagnosis

As the facts of the situation become more real, many emotions begin to surface: feelings of helplessness, loneliness, fear of losing control of the situation and even despair. It is at this point that grieving begins for the family members. They begin to anticipate the grief they will experience when the person they love dies.

There is a search for the meaning and purpose of what is happening. “Why is this happening to us?” They may try to identify the cause of the problem. “If I had only made John go to the doctor sooner.” “If only we hadn’t worked so hard to get ahead.”

Often, there is guilt associated with trying to identify the cause for the illness. It is at this point that the family members may need to hear that nothing they have done or have not done “caused” the illness. It is important to listen carefully to what is being said by the family and to help them deal honestly and realistically with their guilt.

It is also during this time that there is functional disruption of lifestyles within the family unit due to role changes. Time will be necessary for each family member to explore and find the role each must assume so the family can continue to function.

Time and energy will also be required to inform other family members and friends of the situation. This may wear greatly on the immediate family involved with the dying person.

Certain Death

During this time, the inevitable death of the loved one becomes a reality. With this realization comes a sense of impending emptiness and loneliness. There is a real feeling that one is losing part of one’s own life as well as losing the person one loves so much. This confrontation with inevitable death makes people look at their own immortality and finiteness. This may cause many fears and doubts to surface, particularly emotional and spiritual fears. “What happens when we die?” “Is this all there is to life?” “Is there life after death?” “Will I ever see John again?”
Restructuring During the Time of Illness

Ambivalence is the predominant feeling during this phase. There are contradictory feelings of grief over the inevitable death of the loved one and resentment that the dying person is putting the family through so much turmoil. The family may resent the new responsibilities and obligations caused by the illness and inevitable death.

It is at this time that anger and/or depression may be expressed. This is probably owing to ambivalent feelings coupled with physical and emotional exhaustion.

These feelings often lead to limited contact with the dying person because the family members cannot cope with their feelings of ambivalence and the guilt that it produces. This increases the loneliness and isolation for everyone.

Guilt is another problem for family members. They often experience guilt because of their ambivalent feelings. Perhaps the most disturbing thought is that a family member is the feeling of “relief” that they experience when they realize it will soon be over and they can get back to a normal life again.

Another cause for guilt is that many people believe that if they could live their lives over, they could change things, so that the person would not have to die. This often involves things not said or done that they believe should have been said or done.

Guilt is also produced when someone feels that it is unfair that “I live and my son dies.” A family member wishes he could take the things not said or done.

One person may be experiencing denial while another person is angry or depressed. Tension between family members and the dying person is a result of these conflicting emotions (See Figure 2).

As nurses, we may see this tension displayed through angry words or arguments between the patient and his family or it may be evident when the family does not come to the hospital for a few days. It may be important for us to intervene by talking with both the patient and his family and explain that what they are experiencing is a normal response. This may help them understand what others in the same situation are experiencing and reduce some of the tension and conflict between them.

If you have developed rapport with the family, it may be helpful to listen to their concerns and feelings. By being available and listening to them, you may help to alleviate some of the intensity of the emotions they are experiencing. It may be a great relief for them to know that someone realizes and understands they have ambivalent feelings toward the dying person and that it is common for the family to feel this way. In our role as nurses, we may not be able to intervene into the family situation as easily as in the patient situation, but we can be aware of the emotions experienced by the family. This gives us increased understanding of what the family is experiencing and why there may be conflict or distance between the patient and his family. This knowledge should improve the quality of our patient care.

Therapeutic Relationship

Once the family has worked through their feelings, creating a genuine spirit of openness, they can then share their feelings of doubt, apprehension, hope and love with the dying person. The family experiences inner peace and a sense of security and can move beyond their crisis to begin to reach out openly to the dying person with supportive love and understanding. However, the last days will still be difficult and sad and they may still experience moments of profound grief. There is a sense of open communication between the family and the dying person that allows healing to take place.

Bereavement

This phase coincides with the imminent death of the loved one. The family fully experiences their loss and the loneliness of separation.

(Grief will be discussed in more depth in Section III)

So much of what the family faces is similar to what the dying individual faces. It is important to realize that the emotions of the family may conflict with the emotions of the dying person. Each person involved in the situation will grieve over his own losses differently and he will not experience the same emotional responses at the same time that others will.

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Physical Needs Of The Dying

The physical needs of the dying person are the same as they are for any other person. These include such things as good personal hygiene, rest and sleep, activity, safety, nutrition, elimination, and sensory needs. The extent of the need and how it will be met depends on the dying person’s condition at the moment and his own ability to meet the need. Therefore, each situation must be assessed individually and intervention planned accordingly.

There are four other physical needs of the dying person that should be investigated in more depth: pain control; maintaining dignity and self-worth; maintaining control of the environment; and physical love and affection.

Pain Control

One of the greatest fears people have when they think about dying, particularly with cancer, is the fear of intense pain.

Although half of the people who have cancer have little or no pain, everyone fears it, often more than any other aspect of the disease.

The chronic pain of cancer, like that of arthritis and many other diseases, is meaningless as well as endless and it serves no purpose. Generally, when someone is suffering acute pain, we ascribe meaning to the pain and look behind it for a cause that can be treated. However, with chronic pain, there is no meaning and treatment must be directed at the pain itself rather than the disease causing it.

It is important for the dying person to know that his pain can and will be controlled. The goal of pain control is adequate pain relief without sedation. It takes a few days to determine the adequate dosage of a drug and to build a blood level of the drug so that person experiences consistent pain relief rather than cycles of pain/no pain. It is essential to give that drug on a routine basis around the clock to prevent the pain from returning. Adjust the dosages as the person builds a tolerance to the drug. This means either increasing the amount of drug given or the frequency with which it is given. When the adequate amount of medication is determined, the patient will have his pain controlled and still be able to participate in life.

The fear of drug addiction is one of the greatest deterrents to people receiving adequate pain control. Too often, the nurse fears that the patient will become addicted and therefore will not give the medication on a routine basis. “If he is asleep, he’s not having much pain and I
Most people know they are dying and have the right to be consulted in such decisions since it is their life being considered in the decision. A tremendous amount of self-worth and dignity is directly related to our ability to be productive. Often the dying person has been unable to return to work so it becomes important for him to find other ways of feeling productive and useful. Working at hobbies or being creative may be one way of feeling and being productive. Another might be keeping a diary of his experiences and sharing his thoughts and feelings with others who are in similar circumstances. It is important for the dying person to continue to be included in the normal routine of daily life, particularly with his family. This helps him to feel that he is still a useful, productive member of his family and that he can still contribute in some way to its functioning.

Maintaining Control Over the Environment

This need is closely associated with the need to maintain self-worth and dignity because the loss of control affects our self-esteem and how we view ourselves. The sense of the loss of control results from such things as decreased mobility, loss of work, change in financial status and the loss of independence and freedom.

It is important for us to help the dying person find ways he can maintain some control over his environment. Often the area in which nurses can most directly intervene is in the loss of independence and freedom. While he is in the hospital we should allow him to make decisions regarding his daily routine and physical care whenever possible. There is no reason why the patient cannot determine his own schedule of activities, including bathing and personal hygiene, rest periods and activity periods. This provides him with some independence and the sense that he is in control of his life. As already discussed, it is important that

Physical Love and Affection

Physical contact with people is important to all of us. Touch is part of our everyday life. Touch affirms our worth and value as human beings. It shows us that we are cared about and loved and it reassures us that we are not abandoned or alone. Touch provides a sense of physical as well as emotional comfort.

Many times the dying person is not touched or is touched only when necessary. It almost seems as if people are afraid that death or dying is contagious. Even family members are often reluctant to touch the dying person. For some reason it seems that the hospital environment discourages touch as affection with the sick and dying. It is as though the austere and sterile environment would preclude touch for fear of contamination. As nurses, we need to realize that physical love and affection are real physical needs of the dying person. It is appropriate and necessary to provide time and a place for privacy for the dying person and his family so they may demonstrate their love for one another in whatever way they choose.

It is also important for us to touch people at appropriate times other than when we are providing physical care. It communicates to them they are important and are cared for in addition to bringing them comfort.

As human beings, we have many physical needs. The four previously discussed – pain control, maintaining self-worth and dignity; maintaining control of the environment; and love and affection – become more important to the dying person because of the priority he places on them. If these needs are not met, then the daily physical needs become less significant to them. Therefore, these needs should be given special consideration when caring for the dying person.
Spiritual Needs Of The Dying

Often when we talk about spiritual care or meeting spiritual needs of patients, we really think of providing that person with the opportunity to participate in some religious ritual, e.g. the sacrament of communion, baptism, “last rites,” etc.

Even more often, we meet a person’s spiritual needs by calling his priest, minister or rabbi.

Spiritual needs can be more concretely and broadly defined. We can move from looking at symbols or expressions of a person’s relationship with God, to the essence of that relationship itself. While it is important to realize that there are differences in the way people express their faith in God, it is significantly more important to comprehend how similar everyone’s basic spiritual needs are.

The spirit of man is his essence, that part of him that cannot be touched. It is that part of man that does not die but is immortal. Webster defines spirit as “a life giving force” and as “the active presence of God in human life.”

We were created by God to live in harmony with Him. God is the father of all people in the sense of giving all people life and breath. However, the Fatherhood of God and the resulting benefits of kinship can only be fully realized when a person is able to experience God as the source of meaning and purpose, love and relatedness and forgiveness. These three factors contribute to the establishment and maintenance of a dynamic and personal relationship with God. A lack of any one of these three factors will produce a spiritual need.

A spiritual need is defined as “the lack of any factor or factors necessary to establish and/or maintain a dynamic, personal relationship with God.” (Shelly & Fish, p. 39) Because God is the source of these factors, a relationship with God is established and maintained as a person responds to God in obedience. We are able to respond to God in obedience because of the grace he has freely given to us through the death of Jesus Christ. Anything that impairs a person’s ability to sense God’s desire for a relationship with him can make that person feel hopeless, unwanted and unloved.

The basic spiritual needs of all men are:

1. The need for meaning and purpose
2. The need for love and relatedness
3. The need for forgiveness

How does a spiritual need differ from an emotional need? An emotional need concerns itself with the relationship of a person to his own emotions and to himself while a spiritual need concerns itself with the relationship of man to God. A spiritual need is God-centered while an emotional need is self-centered. Let us examine the three basic spiritual needs in more detail.

The Need for Meaning and Purpose

Throughout history, man has searched for the meaning of life. This search for meaning is one of the primary motivators that keep us going. When a person comes to a place where his life makes no sense and there seems to be no meaning or purpose in living, he becomes depressed and indifferent toward life. If he reaches a place where he can find no hope for meaning and purpose in the future, he longs for death.

Where do we find ultimate hope and meaning for our lives? Ultimately, secure hope with meaning and purpose comes from God. Some degree of hope is possible without knowing God, but this hope is temporary and insecure. Trying to find meaning and purpose in life through ourselves, others or circumstances can only be temporary because these all change. People leave us; circumstances change daily in our lives; and who can truly trust himself? We most often end up disappointed and disillusioned.

The fact that God is in control gives ultimate meaning and purpose to any situation. This is true because God never changes and because God lives forever. Hoping and believing in God does not mean an abrupt end to problems in life, but it does mean we never have to face life or its problems alone. A person who senses God’s direction in his life is able to adapt to any unexpected changes. He has hope even when everything around him falls apart because God has promised to those who believe in Him: “I will never leave you or forsake you.” (JOSHUA 1:5)

This relationship with God will be important for the person searching for meaning and purpose in the face of death. There is no hope in life or people because he will soon be leaving all of this behind. His search for meaning and purpose focuses on his future. If he believes there is nothing beyond this life, then he will have no hope and can find no meaning and purpose in either his life or his death. If, however, he believes in God, who is the giver of life and in Jesus Christ, who is the hope of eternal life, then he has great hope and anticipates the life that will continue for him.

The Need for Love and Relationships

The need for love and to be in relationship with others is common to us all, for God created us with this need. This need is evident from the beginning for the Bible tells us that God created man to be in fellowship with all that was created. God said: “It is not good for man to be alone.” (GENESIS 2:18). Therefore, God created a suitable partner for the man. Man is and always has been a social being.

The emotional need for love and relationship is met in the context of significant human relationships. The spiritual need for love and fellowship is met only through a personal relationship with the eternal God. Let us look at this more closely.

There are three types of love that all of us have experienced in our lives: the “if” kind of love, the “because of” kind of love and the “in spite of” kind of love.

The “if” kind of love says: “If you satisfy my needs then I will love you.” This type of love is conditional, motivated by self-interest; and there are always strings attached. Unfortunately, the “if” love is common today and many relationships are broken when the conditions are not met.

The “because of” love says: “I love you because of what you have” or “I love you because of who you are.” There is a sense that this type of love has to be earned or there is a burden of fear. This fear results from “What if I lose the very thing I am loved for because of...?” Any form of illness can reinforce the belief that the ill person has never really been loved for himself alone.

The “in spite of” love says: “I love you no matter what.” It is unconditional and there are no strings attached. This type of love is not deserved or earned; it is freely given. You are simply loved as you are, in spite of your faults and failures. You may feel worthless and yet you are loved as though you have infinite value and worth. This is the kind of love that our hearts are desperately hungry to have. We all long to be loved this way. Only God is capable of truly loving us in this unconditional way. We can try to love one another this way — and we can to a point — but somewhere along the way we set expectations or make demands on the other person. A person who is experiencing God’s unconditional love sees himself as a person of worth; and this frees him to love God, himself and others.

God is the only true and lasting source of love. Our relationship to Him will last forever.

The “in spite of” love is important for the
dying person because he is no longer in a position to earn love from others or to try to meet the conditions required to obtain love from others. Therefore, it is important for those around him to encourage and support his belief in and relationship to God through prayer and appropriate use of Scripture.

The Need for Forgiveness

Guilt is one of the biggest burdens in our lives. It seems to loom around every corner of life. Where does guilt come from?

Guilt results from the failure to live up to expectations, either our own or those of others. The type of guilt created by this sense of failure false guilt. We are not guilty of anything; we just feel we are. When we experience this type of guilt we are quick to try to rationalize it, deny it or make amends for it. We try hard to obtain forgiveness from the offended party so that we can once more live in peace. This can meet our emotional need for forgiveness, but it is only temporary for we soon have to repeat the process all over again.

True guilt comes because of our rebellion against God and the standards He has set. This type of guilt not only brings guilt feelings but it actually separates us from God’s presence. Whether we realize the impact of that separation from God at the time, eventually it brings a sense of shame, the knowledge that we cannot look God in the eye and the fear of His judgment and punishment.

Confession of sin to God is the means God has provided to pave the way to receive forgiveness. True guilt cannot be dealt with effectively by rationalizing it, by denying its existence or by promising to do better the next time. True and lasting forgiveness comes only when a person confesses his sin, admits his own inability to rid himself of it and exercises faith in the forgiving power of God through the death of Jesus Christ. This forgiveness is ultimate and eternal. The person who knows God’s forgiveness will be at peace with God, himself and with those around him.

It is important for the dying person to realize forgiveness for both false and true guilt. The dying person needs time to settle differences and to receive forgiveness from God and others if he is to die in true peace.

The spiritual needs of patients are often avoided and neglected even though they are recognized as important in this era of “wholeness.” The cry of the profession is to meet the needs of the whole person and yet we are taught to meet the biopsychosocial needs of people with little if any mention of the spiritual aspect of man’s needs. Why is this? There are two major reasons that contribute to this:

1. Many people have not recognized and had their own spiritual needs met, so they are uncomfortable with assessing spiritual needs in others.
2. Religion has always been considered a private matter and not one to be discussed. How often have you been told that it is important to assess a person’s physical situation related to his bowel movements or his sex life? Aren’t these private matters as well? Nursing is an intimate profession.

Should a nurse be interested and involved in meeting the spiritual needs of people? Yes! Spiritual intervention is appropriate if we care about our patient’s spiritual life as much as we care about his physical and emotional well being. Not meeting his spiritual needs can be as negligent as not meeting his psychological and physical needs.

When assessing spiritual needs of the dying, it is important to evaluate each situation carefully, using the nursing process. Spiritual care should not be given haphazardly or with pat answers. Each individual is unique and so are his needs.

In assessing and meeting spiritual needs there are four resources available: the therapeutic use of self, the use of prayer, the use of Scripture and referral to clergy.

The Therapeutic Use of Self

In using ourselves in a therapeutic manner, we affirm to each patient that he is a person worthy of our time and involvement. This means relating to individuals in a supportive, caring way without the use of props. This means being as opposed to doing.

To be able to relate to people in this way means that we must be confident in who we are and in what we believe. If you do not know what you believe about dying and death, you will not be comfortable helping someone face death. Therefore, relating to dying people would raise all kinds of questions and fears in your own life, which could render you helpless in the situation. On the other hand, if you are comfortable and confident in your beliefs about death, you will convey that to the person and you will be helpful to him.

Therapeutic use of self involves skills such as listening, empathy, vulnerability, humility and commitment. To understand what a person is feeling and to feel with him while remaining objective is a difficult task, but it can be accomplished with faith, education and practice. We need to be willing to continue in a relationship as long as that person needs spiritual support. We will experience pain and grief as we get involved with people in this way, but there is reward in knowing we have helped the person through one of the most difficult and stressful times in his life.

When we meet spiritual needs through the therapeutic use of self, we often represent God to our patients. How we relate to and care for that person may determine his perception of God’s love. However, our goal in meeting spiritual needs of patients is to direct their dependence toward God and not ourselves. This means that the therapeutic use of self in meeting spiritual needs is insufficient by itself, so we need to use other resources as well.

The Use of Prayer

Prayer is intimate conversation between us and God. True prayer is a dialogue. It is openness to God’s will as well as a statement to God of our requests, thoughts and feelings. When we have a dynamic, personal relationship with God, prayer is a vital lifeline in that relationship, just as good communication is essential in developing and maintaining any intimate friendship.

Illness and crisis can create a barrier to personal prayer and ultimately to God. The dying person may think God does not hear, does not care or does not know about his concerns. He may be angry with God and refuse to talk with God. In addition, he may be so overwhelmed with the situation that he feels no one, including God, could help him. Our prayers for the dying person are important because God hears our prayers and answers them. However, it is also important to pray with the dying person whenever appropriate. By praying with the person, we bring him with us to God in prayer. Thus, we affirm the presence and active concern of God in his life. This may help to reestablish his relationship to God by breaking down barriers that may have previously existed.

Prayer must be used in conjunction with the therapeutic use of self. Establish rapport with good communication before praying with a person. Praying when we do not have a clear understanding of what is bothering the person is likely to cut off further meaningful, in-depth communication. Prayer should not be used to end a conversation because prayer often triggers deep feelings that may need to be discussed after praying.

A basic guideline to use in determining the appropriateness of prayer is “Whose need am I meeting — my own or the patient’s?” Do not pray because it is the thing to do or because you
do not know what else to do. If it were your need that compels you to pray, then it would be better to pray privately or with a friend about the situation rather than to use the patient to meet your need.

When we pray we bring comfort and encouragement through facilitating the person’s relationship with God. It is important for us to realize that there may be other ways of facilitating their relationship with God, such as providing a period of privacy for personal devotions or an undisturbed visit with a clergyman.

It is important to assess what the dying person’s need is concerning prayer and to intervene appropriately.

**The Use of Scripture**

The Scriptures are God’s personal communication to us. They are the truth of God expressed in words. Their primary purpose is to enable people to establish a dynamic, personal relationship with God. The Scriptures also teach us how to live in harmony with God, others and ourselves. The Bible gives us the true means for finding meaning and purpose, love and forgiveness.

Illness and crisis produce disequilibrium and instability in our lives. The Bible can provide hope in crisis and meet spiritual needs because it focuses our attention on a stable, dependable God. The Scripture can provide comfort and encouragement for those who are suffering.

It is important to assess the dying person’s need and desire for Scripture. When Scripture is used appropriately and in a meaningful way, we can help bring the dying person to God to receive hope, love, forgiveness, encouragement and sustenance. Most often, the nurse will be most effective when she is able to share from her own relationship to God a Scripture that has been meaningful to her, and one that is relevant to the needs the dying person is expressing.

Inappropriate and misapplied use of Scripture can cut off meaningful communication with the dying person. Premature use of Scripture can be like putting a bandage on a wound that needs to be open to the air. The wound collects moisture; and in its darkened environment bacteria grows and the wound becomes infected. If, instead, the wound were exposed to the air and cleansed, it would heal. This means that it is important to listen to determine the person’s real need before we try to meet the need.

A nurse who uses Scripture too quickly without assessing the person’s need can communicate that God is impersonal and that He has a pat answer for every question. Pat answers from the Bible can alienate the dying person further from God. They also reinforce the idea that the Bible is merely a book of rules and regulations – a book of judgment rather than comfort.

The patient’s need is our primary guide for determining the appropriate use of Scripture. Again, it is important to ask the question, “Whose need am I meeting? Am I meeting the patient’s expressed need or my own need?” If the nurse has a need to witness or do evangelism, then she should do it in an appropriate context, not in the hospital. She should not be motivated by guilt to do evangelism. This only drives the dying person further from God. This does not mean that a nurse never shares how to establish a relationship with God, but it does mean that the sharing must be properly motivated and be in response to the patient’s expressed need.

The appropriate and effective use of Scripture in meeting spiritual needs is a skill that can be developed. We develop that skill by developing a personal relationship with God, by gaining personal knowledge of the Bible and becoming aware of our motivation for using Scripture to meet spiritual needs. Appropriate use of Scripture brings comfort and encouragement to those with whom we share.

**Referrals to the Clergy and to Other Nurses**

The clergy are another resource in spiritual care. The ministry of the clergy and the spiritual care given by nurses should complement one another. For us to function together effectively we need to have the common goal of caring for the whole person, we need to realize that we have distinct yet complimentary roles and we must have open communication.

There are many times when, as nurses, we need to call on other members of the health care team to assist the patient in meeting his needs. Because of their experience and education in the area of spirituality, clergy are often a helpful resource in assisting the dying person in meeting his needs for love, forgiveness and hope. Clergy may be particularly helpful in the area of forgiveness because people perceive them as being able to absolve sin; therefore, people feel more forgiven when a clergyman helps them deal with their sin and guilt.

Referral to other nurses may also be helpful in meeting spiritual needs of people, particularly if you are uncomfortable with intervening in this area of need. It would be appropriate to ask another nurse who is comfortable with spiritual needs to talk with the person, especially if she has already established rapport with him. She could then assess the situation and intervene accordingly. We are not reluctant to ask others to assist us in meeting emotional and physical needs of those we care for; neither should we be reluctant to make referrals about spiritual care.

Referral to clergy and other nurses is an effective means of assisting the dying person in meeting his spiritual needs.

Our effectiveness in meeting the spiritual needs of those we care for is dependent on the harmony we experience with God, others and ourselves. We need a confident sense of meaning and purpose in our own lives in order to assist others in finding meaning and purpose. We need to experience the love of God and other people to be able to love those we care for. We need to know personal forgiveness from God in order to communicate forgiveness to others. Spiritual needs, both our own and those of the dying, are met by God, who is the author of love, forgiveness and hope.

**The Nurse’s Role**

What is the nurse’s role in all that has been previously discussed? What are some ways in which we can help meet the needs of the dying person and his family? First, the nurse should define her own personal philosophy of life and death. What do you believe? What does human life mean to you? What is death and what does it mean? Is there life beyond this life? Is there a God? Is there a heaven and a hell?

Why is it important to know what you believe about these issues? To be helpful to others, you must be comfortable and confident in what you believe. If you are not, then you will be threatened and even fearful when confronted with dying and death. When you experience this type of tension within yourself, you spend most of your energies protecting and intervening accordingly. We are not reluctant to ask others to assist us in meeting emotional and physical needs of those we care for; neither should we be reluctant to make referrals about spiritual care.

Knowing what you believe and your limitations will help you meet the needs of the dying person and his family more effectively.

Second, it is important as a professional to be able to accept the dying person and give validity to his feelings. We should not expect people to respond as we think we would respond or as we think they should respond. We are all
individuals with unique personalities and we all have different ways of coping with situations. When we do not accept people where they are emotionally, they feel judged and often condemned. This puts distance between us and renders us helpless and ineffective in meeting their needs. Therefore, it is important for us to accept them and their feelings, even when we do not always agree with them.

Third, we are to be advocates. This means that as nurses, we act for the dying person to insure his rights and to make his dying easier. We do this in several ways:

1. We need to be available to the dying person and his family. This means that we listen, answer questions honestly and talk with them about their feelings. Our goal should be to develop a personal relationship with the dying person not just take care of his physical needs.
2. We need to help in facilitating communication. This may be a communication between the dying person and his family or the dying person and his physician. The dying person has the right to be included in making crucial decisions relating to his life and his family.
3. We facilitate communication by bringing people together so they can talk openly and honestly.
4. We need to make provision for significant others to be with the dying person. This may involve modification of hospital visitation policies. This is important so the dying person does not feel alone or isolated from those he loves.
5. We need to insure that his physical needs are taken care of. This is particularly important in the area of pain control. We must communicate with the physician to make certain the dying person is kept comfortable. We must also make other arrangements as necessary to provide for his physical comfort.
6. We need to make referrals for the dying person when appropriate; for example, asking the social worker to aid in the area of financial needs or discharge planning or asking the chaplain to visit a person who has expressed a spiritual need.

Being an advocate involves many different aspects of nursing care. Our focus must always be on meeting the needs of the dying person and his family and making the dying process easier whenever possible.

The nurse’s role in working with the terminally ill is not an easy one. It involves many difficult decisions and serious responsibilities. Nurses make many judgments about continuing and discontinuing treatments, answering questions and providing explanations to patients and families, communicating with physicians and taking the necessary steps to provide physical comfort for the dying person.

In many ways, terminal care is a curious mixture of the traditional tasks of nursing and interpersonal aspects of nursing which helps the dying person in maintaining personal contact with the social world he is about to leave. The challenge of nursing in terminal care is both difficult and rewarding.

**Communication With The Dying**

Communication is an important part of caring for the terminally ill person and his family. To communicate effectively with the dying person, there is some basic information that is important to know and utilize in your daily nursing care. Communication takes place whenever there is an encounter between two people. We communicate through such things as our appearance, behavior, posture, facial expressions, mannerisms and gestures. Communication takes place whether we are aware of it or not.

What is communication? Webster says that communication is giving or exchanging of information, signals or messages by talk, gestures, writing, etc. Communication is also a process by which a source develops and transmits a message through some channel to a receiver. For communication to be effective, it must be reciprocal. If the message sent is not received and understood, the communication is ineffective.

**Modes of Communication**

Modes of communication include written, verbal, non-verbal and meta-communication. For the written word to be an effective form of communication, the receiver must understand and react to the ideas and concepts that the author is attempting to convey. If the reader does not receive the intended message, successful communication is not achieved.

Another mode of communication is the spoken word. If the people who are talking together understand the same language and share similar meaning of words, they can communicate.

Non-verbal communication refers to messages sent and received through such means as facial expression, posture, behavior, voice quality and gestures. The non-verbal aspects of communication sometimes convey general attitudes, feelings and reactions more clearly and more accurately than the spoken word.

It is important to understand the implications of non-verbal communication so that we are aware of what others are saying to us and are aware of the messages we are sending to others. The nurse who works rapidly, walks down the hall briskly and answers questions briefly is likely to communicate that she does not have time to spend with the dying person. This behavior also communicates that the nurse is uncomfortable and is trying to avoid the dying person.

Another mode of communication, which is rarely recognized on a conscious level, is meta-communication. Meta-communication refers to the role expectations individuals have of one another. These role expectations strongly influence the nature of verbal and non-verbal communication. For example, when a sales person says to a customer, “May I help you?” it is understood by both individuals that the sales person is asking whether she can be of assistance to the customer in making a purchase. On the other hand, when a nurse asks the same question of a patient, it is understood by both that she is asking if there is something she might do to help meet his physical needs.

Meta-communication and non-verbal communication are present in all situations where there are two or more people, although verbal communication may be absent at times.

**Types of Communication**

Two types of communication that we are familiar with because we have all experienced them are monologue and dialogue.

Monologue is one-way communication.

In a monologue, the speaker is preoccupied with himself and what he believes. He often loses touch with those to whom he is speaking. The conversation is parasitical because he is not interested in others and values them only according to the feelings they produce in him. He tends to be anxious and fearful of personal encounters and tolerates only agreement with himself and his ideas. He is also uncreative because his world is a closed one. That is, he seeks to present his own meaning as final and ultimate. We often see this type of nurse as one who has all the answers and acts as if the patient has no knowledge at all. The nurse is the final authority and does most of the talking without doing much real listening. She is quick to tell the person not to worry and how he should feel and behave. Have you known any nurses like this?

Figure 3 indicates that monologue is one-way communication.
Dialogue, on the other hand, is an interaction between persons in which one person seeks to give himself as he is to the other person and seeks also to know the other person as he is. This means that one person does not attempt to impose his views and beliefs on the other person. Rather, there is a flow of meaning between the two people. It is important to see an event from the view of the person you are talking with as well as from your own perspective.

It is important to realize that dialogue is a principle, not a method.

The principle of dialogue is openness to the other person, with a willingness not only to speak but also to respond to what we hear.

Either type of communication, a monologue or dialogue, can utilize the dialogical principle. For example, a monologue can be used with the dialogical principle in a creative lecture in which the lecturer is alert to his audience and involves them in what he is saying; there is openness between them. What is important to remember about dialogue is that it is a reciprocal relationship: both sides speaking, hearing and responding in an open, meaningful manner.

Figure 4 indicates that dialogue is a dynamic, reciprocal process.

Listening is an important part of dialogical communication. Listening is an active process that requires energy. It involves the ability to focus one’s entire attention on the other individual. People often hear but seldom listen. Listening involves hearing and interpreting what the other person is really saying.

Empathic listening increases trust between people and is critical to the development and maintenance of a mutual relationship. Empathic listening involves a determination of what the other person is saying, the content of his message, listening for the way he is saying it and understanding his feelings and attitudes. Sometimes the feelings and attitudes conveyed contradict the spoken message. When person a says “I’m fine” and his attitude is one of sarcasm or defensiveness, you would probably interpret that he is angry that all is not “fine.”

Listening, active listening, is not easy for any of us. It is a skill learned and one that we must practice to be effective.

**Purposes of Communication**

What are the purposes of communication? Why do we bother to communicate with others?

1. Communication is a means of conveying information to one another. We need to make available to people the knowledge and skill that has accumulated from the study and experience of generations of people. This information helps us learn and grow as individuals and helps to prepare us for the second purpose of communication.

2. A second purpose of communication is to help people make responsible decisions, whether the decisions are positive or negative in relation to the information given. It is important not to judge their decision as right or wrong, but it may be important to help them clarify alternatives and to make sure they mean what they say. In the situation of treatment for cancer, it is important to make sure that patients understand the ramifications of their decision whether it is to be treated or not to be treated. This purpose of communication is to translate word into action.

3. The third purpose of communication is to build relationships between people. As we share ourselves through open dialogue, others know us and we get to know them. What we choose to communicate determines how much others know us. In addition, how we respond to what another shares with us will help determine how much of himself he will communicate to us. Without effective communication, relationships will be difficult to develop and hard to maintain.

**Barriers to Effective Communication**

We have looked at what communication is and what is involved in effective communication between people. However, what about ineffective communication? Listed are some of the barriers that cause communication breakdown.

1. Failure to perceive the person as a special human being. Stereotypes and preconceptions color our opinions of people. These mind-sets hinder us from responding and appreciating the uniqueness of others. Example: “All cancer patients are terminally ill.” The conclusion is that there is no hope for anyone with cancer.

2. Failure to recognize levels of meaning in communication. It is important to remember that a message may have meanings other than the apparent “obvious” literal meaning and that failure to recognize this may cause a breakdown in communication. Communication is also blocked when some statements are accepted at face value without exploring the person’s meaning and intention. Example: The nurse asks a patient “How do you feel today?” The patient replies, “Pretty good.” If the nurse accepts this reply at face value, she may assume that all is well. However, the patient may really be saying, “I feel better than yesterday” or “The pain isn’t too bad,” or he may be saying what he thinks the nurse wants to hear.

3. Failure to listen. Failure to listen is a major cause of communication breakdown. The nurse may not be willing to expend the energy necessary to listen actively; she may be tired, preoccupied, bored or irritated with the individual. Failure to listen may be a result of the nurse’s talking too much and interrupting the individual when he is trying to talk with her. Sometimes she changes the subject. Failure to listen is interpreted as disinterest in people as individuals. People will be reluctant to share meaningful things with us if they feel we are not listening.

4. Using value statements with reflection. Using value statements, such as “Isn’t that wonderful?” or “That’s great” before discovering how the person really feels about the situation may block further meaningful communication. For example, an individual tells a nurse that he has lost another five pounds and the nurse responds, “That’s great!” The person may not think, “That’s great,” and may be concerned about his weight loss. He would like to verbalize his concerns to the nurse about his fear of cancer but probably will not because he feels the nurse really is not interested.
or that she would not understand. It is important to explore the meaning of the statement with the person instead of operating on the assumption that everyone is excited about losing weight.

5. Clichés and automatic responses. These include the use of trite, tired, meaningless phrases or statements. They are often used without reflection or thought by the nurse. Pat answers and stock replies maintain distance between people. They keep us from getting too involved. Example: “Am I dying?” “Of course not, you’ve got the best doctor in town” or “Don’t worry, you’re going to be just fine.” The nurse may not know what to say and is more comfortable using a cliché. Nurses who use them may mean well, but they fail to reassure the dying person or to meet his need; they block further meaningful dialogue.

6. Accusing, blaming and teasing. Another effective means of blocking communication is to accuse, blame or tease the ill person. Some nurses blame the ill person and verbally accuse him of causing his own illness or give the impression that they are busy and not about to waste time on someone who caused his own illness.

“If you hadn’t smoked so much, you wouldn’t be dying of lung cancer now. You should have known better.”

Another problem is teasing done as an attempt to induce guilt and shame in a misguided attempt to effect change in a person’s behavior. A nurse may imply that the person is “too old” or “too big” to behave in such a childish manner.

Behaviors such as accusing, blaming and teasing are not only unprofessional, they are cruel, punitive and inhumane.

The above are some of the barriers to effective communication. Although not all breakdowns in communication can be prevented, they can nearly always be recognized. To recognize these breakdowns, the professional nurse should continually evaluate her ability to communicate with others. It is important to consciously work to improve this skill.

Effective communication is a key to working with dying individuals and their families in a meaningful and helpful way.

Why is it that talking with a dying person is so difficult? Many times, we are afraid we will say the wrong thing, so we do not say anything. On the other hand, we are afraid the person will get upset and we will not know what to do to help. So, again, we avoid him or talk about superficial, totally unrelated subjects like the weather or our day off. Is it any wonder the dying person feels alone and isolated?

A problem we face in our communication with the terminally ill is determining what needs to be communicated and how much to tell them. Two questions will be explored in the following section that should help us deal with this problem:

1. Should a person know he is dying?
2. Do the dying really want/need to talk about death and what it is like to be dying?

Should a person know he is dying? Yes, he should know. The telling can come in different ways, but he should be told. There is a myth that says, “If a person knows he is dying, he will be more anxious.” This is not true. Just the opposite is true. The more a person knows about what is happening the less anxious he is likely to be.

Ambiguity creates anxiety. Studies have shown that the overwhelming majority of informed patients adapt favorably to the news of their illness, while the uninformed are not only unaware of the nature of their disease, but often learn about their condition from outsiders. When this happens, a sense of distrust develops and the person’s anxiety level increases. When it becomes evident that people around him are not being honest, he suffers the pain of betrayal and often feels alone and helpless.

If a person is not told, but is suspicious, he seeks to find out the truth. There are several clues he uses to gain information and learn the truth:

1. There is no improvement in his condition or if there is improvement, it does not last.
2. His symptom progress and new symptoms develop.
3. He suffers overwhelming exhaustion: his inability to gain strength and stamina cuts into the quality of his life.
4. He receives verbal hints from other people — “Don’t worry, you’ll be fine” or “You’ll have to ask the doctor.”
5. He does not receive information about tests or his information is in the form of scientific terminology that is not explained in simpler terms.

6. He observes facial expressions and actions; avoidance behavior or looks of pity that were not there before.

7. He receives treatment protocols that are not explained.

People who do not know frequently suffer the distress of uncertainty and find themselves unable to share their fears and concerns with anyone. This intensifies the feelings of loneliness and helplessness.

In a study done by Glasser and Strauss, in the late 60’s, the following four states of awareness of dying were described:

1. Closed awareness — others know the person is terminally ill, but the patient himself does not know. This leads to evasion and lying about the expected future. In this situation, the patient will probably sense that something is wrong, stress and insecurity will build, and yet no one will tell him the truth. Therefore, he remains alone in his fear and concern.

2. Suspected awareness — this is a middle state between knowledge and ignorance. The individual suspects he is dying, but is not sure. He watches for clues and attempts to find out the truth. This state is destructive to security causing swings of emotion between fear and hope. Significant communication and support from others is limited due to the supposed state of unawareness of the dying person.

3. Pretense — in this state, both the patient and others know that he is terminally ill, yet both tacitly agree to act as if it were not true. This pretense threatens security and blocks development of supportive relationships and communication.

4. Open awareness — in this state everyone knows the seriousness of the situation and acknowledges it openly. This open context allows the patient to deal with reality and allows those around him to be helpful and supportive. This is the ideal and should be the goal of communicating with the dying person and his family.

If his doctor has told the person that he is dying but still does not seem to understand, he may be in denial; possibly, he has not understood what the doctor has told him. People want to understand, not only their diagnosis, but also what that diagnosis means and what is going to happen to them.

How, then, do we explain things so people understand? They need to know what is happening to them, but they need to know gently, gradually and at a rate determined by them. Careful, sensitive listening is the key. Do not force the issue. Give them the information
in installments as they ask for it. Answer all questions honestly, using language they will understand. Answer only the question; do not offer other information unless they ask for it. Listen to the reaction you get and respond appropriately. Offer them realistic hope but never false hope. This may mean helping them understand that even though there is not a cure, but there is a lot we can do to help them live comfortably with quality.

If the dying person thinks you are uncomfortable with the truth or with his impending death, he probably will not share his innermost feelings and fear with you.

When we refuse to answer questions or when we beat around the bush, we communicate a lot of information. Many times, it is wrong information or it is misinterpreted; the person then makes incorrect assumptions about what is happening or going to happen to him. It is important for us to be as honest and direct as we can when dealing with the dying person and his family.

Do the dying really want/need to talk about death and what it is like to be dying? The myth associated with this question is: “Shouldn’t we get his mind off it?” The answer is no, not necessarily. It helps most people to talk about their situation. Talking often relieves anxiety and helps them face reality. It may also help to decrease anger and depression. When others genuinely care, are empathetic listeners, are willing to openly and honestly speak with the dying person, they can be as effective as professional counselors. Most often people do not want answers or solutions to their problems; they just need someone who cares and is willing to listen.

The most important but least asked question is “How do people who have what I have generally die?” A person’s fear of the unknown may cause him more anxiety and stress than the truth would. Again, it is important to be honest, but there is no need to be cruel. Make sure you know what he is really asking; then answer the question, simply and honestly. There is no need to go into any gruesome detail. Most people are really asking such things as: “If my cancer spreads, where will it go next?” “Will I be able to think clearly and how to live with his illness and his prognosis. It is important for him to know what others with similar illnesses have faced as they have approached death. If this is information that you do not know, find out from other available resources, e.g., the library or other nurses. A clinical nurse specialist in oncology or med surg. nursing would be a valuable resource for this information. Families have questions too, similar to those of the dying person.

They need the same type of open, honest communication from us. The family will want to know “What will we have to endure?” “What will his death be like?” “What will we as a family be able to do for him?” Open, honest communication will not automatically occur between the dying person and his family. Sometimes people need help getting started because it is so difficult for all involved.

This may mean that a third person, you, the doctor, a clinical specialist or a clergy, may need to sit down with the family and the dying person and talk specifically about the situation. It is important to realize and remember that families that cope well with crises are those that have had good communication with one another before the crises have occurred. If there were problems and conflicts before a crisis, the problem will not go away or resolve itself because a crisis has occurred. Often the problems only get bigger and distance grows within the family.

It is important to talk with and listen to those who are facing death. Communicating important information about their condition and their prognosis allows people the time necessary to get their lives and their personal business in order. It also allows them time to make reconciliation with others and with God, if necessary and provides them with the opportunity to say good-bye to those they love.

The Nurse’s Role

The nurse’s role in working with the terminally ill can be a special one. It is an opportunity to participate in a personal event, even intimate, with the one who is dying. It becomes a privilege to share in this experience with the dying person.

How can we get involved in sharing this experience? Establishing a trust relationship with the dying person is the first step. This is accomplished through open, honest dialogue and by demonstrating empathy toward his situation. We must earn the right to enter into his situation by showing him that we care and really want to understand what he is going through.

Active listening is also important. Listen with your “third” ear. Hear what he is saying between the lines. Hear what he is not saying but would if he could. Try to understand his feelings and thoughts from his perspective.

Communicate acceptance of his feelings. Do not make light of them or place expectations on his feelings. Allow him to share his feelings and his fears without passing judgment on them.

Even if you do not agree or do not understand, his feelings are real and valid to him. Avoid such phrases as “Don’t cry,” “Don’t worry,” “You shouldn’t feel that way,” or “You’re so brave.”

Understand the important role of non-verbal communication in relating to the dying person. Touch is vital. His distress and loneliness are alleviated with your touch because you are physically entering into his world and his situation. Do not stand over him; sit beside him. Your facial expression will tell on you. See the person first, not his disease or his death. Our feelings are often revealed through our eyes and facial expression.

Listen to what you are saying to others. Be sensitive to the content of your message. Be willing to discuss the trivial as well as the intense with him. Be sensitive to who is directing the conversation. Are you allowing him to direct the flow of conversation or are you? Avoid talking about yourself too much. This implies that he is not important to you and he might decide you do not care what is happening to him. Avoid talking about other patients with other nurses when in his presence. He will believe that you cannot keep information in confidence.

The nurse should be a facilitator of communication by encouraging the dying person to talk about what is happening to him. She also facilitates communication by bringing people together and helping them to communicate. Sometimes this is as an advocate between doctor and patient so the doctor tells the patient what he needs to know about his diagnosis and prognosis. This may mean asking questions of the doctor in the presence of the patient to get an answer. For example: “Dr. Jones, Mr. Doe wanted to ask you about his CAT scan.” “Did you say that Mr. Doe’s CAT scan results were back?” You may simply tell the doctor what the patient needs to know and ask him to talk to the patient about these concerns.

There may also be times when the nurse will need to start communication between family members and the dying person. This will help them move from a state of pretense to a state of open awareness. If communication has been
open between the family and the dying person before his illness, it may just take someone to help them get started talking, someone to help them see the need to share openly their hurt and their love for one another. If communication has been superficial or closed, it may be difficult or even impossible to get them to communicate with one another.

This is important information for us to know and to practice, but we must be realistic.

We will not “click” with everyone we care for. Sometimes personality differences prevent us from communicating effectively with some people. We must realize that we cannot spend extended in-depth time with every person we work with, so we need to be aware of those we relate to easily and determine which of our patients need and want our time and energy. Some people will not accept our care and concern no matter how hard we try; and all dialogue has to be mutual to be effective and beneficial.

Owing to fatigue and a heavy workload, we will not be able to spend in-depth time with people every day. If we have established a trust relationship with them, they will not need us to be with them every day. Most people do not even expect us to be available all the time; that is our expectation of ourselves. They will know, however, that we will be there when they really need us. It is important for us not to set expectations of ourselves too high or we will be disappointed with ourselves. Remember we are all learning and growing. We will make mistakes, but we must keep trying. Effective dialogue is an important part of working with the terminally ill.

Grief

What is grief? It is an emotion or a complex of emotions we experience when we lose someone or something we value. Grief is a natural part of life. We have all faced the losses of people and things we value throughout our lives. Can you recall your first encounter with loss and grief? Was it your favorite pet or a toy? Maybe it was the loss of a parent through divorce or death. How did you feel? What emotions did you experience? Did you experience loneliness, sadness, emptiness or hollowness, depression, fear, isolation, anger, rejection, confusion, nausea, or the feeling that no one understood? These are just some of the feelings experienced during the time of grief.

Grief is a personal thing. It does seem as if no one knows or understands the depth of our sorrow. It is not true. Others have hurt and suffered. Their experience may have been different, but that does not mean they cannot understand. What is even more important for us to know and understand is that God knows the depth of our grief because He has experienced grief. All that He created has rejected Him and turned away from Him. God knows grief. He sent Jesus Christ to be sacrificed for our rebellion so that we could be fully reconciled to God. God knows suffering — He died on a cross.

It is God’s desire to comfort us in our sorrow, and it is His desire that we comfort one another:

“Praise be to the God and Father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles so that we can comfort those in any trouble with the comfort we ourselves have received from God.” (1 CORINTHIANS 1:4)

To better understand what people experience during the time of grief, let us examine the various aspects of grief and what is involved.

Types of Grief

There are two types of grief: anticipatory and unanticipated. Anticipatory grief involves a time or period of preparation for the loss. When we consider terminal illness, those dying of a chronic illness, there is time for the person and his family to anticipate and prepare for his death. In unanticipated grief, there is no time for preparation because the loss occurs suddenly; e.g., accidental death or cardiac arrest.

The importance of preparatory grief is:

1. It gives the dying person important time to prepare for his death by taking care of his “business” and getting things in order.
2. It allows the family and significant others the needed time to prepare for the loss and helps to make the adjustments and arrangements after the funeral easier for them.

Anticipatory Grief

For the person who is dying, preparatory grief includes the “stages of dying” already discussed. For the family and significant others, anticipatory grief involves going through four phases:

1. Depression — This is the first response to the news of impending loss. This often includes a period of anger and self-pity. The family is more concerned about their feelings and their loss than they are about the person who is dying.
2. Heightened concern for the ill person. The family has worked through their own feelings, at least to a great extent, and become concerned about what is happening to the one they love who is dying. They suffer with and for their loved one. During this time, the family has the opportunity to do all they need to for the dying person. They can say what needs to be said and meet the physical needs of the person thereby decreasing the feeling of guilt after death that says, “I should have done more.”
3. Rehearsal of the death — As death becomes more imminent, the family anticipates their loss and begins to muster up the appropriate coping mechanisms which will help to decrease the impact of the death when it occurs. This gives the family the opportunity to brace themselves for the inevitable loss.
4. Attempt to adjust to the consequences of the death — By their preparing for the death the post-death period becomes better controlled for the family. They have the opportunity to learn what needs to be done and how to do it in the absence of the dying person. This helps people feel less helpless and better prepared to face the tasks of daily life. It also provides time to find out the wishes of the dying person about important matters such as rearing the children, selling the home, and other financial or business affairs.

Even though people have time for preparation, death is still traumatic when it finally occurs. However, its cause is more readily understood than in unanticipated death.

Unanticipated Grief

In unanticipated grief, the death is sudden and unexpected. Its cause is never really understood, and the survivors often fear that the event causing the death could occur again to someone else close to them or to themselves. This is particularly true when the death is caused by an accident.

Normal Grief

Everyone experiences grief. Some Christians believe that they should not grieve because there is no need for sorrow or grief when their loved one is in heaven. This belief is unfair and, I believe, not Biblical.

In Matthew 5:4, Jesus tells us, “Blessed are those who mourn, for they will be comforted.” To be comforted in the face of grief, one must sorrow and mourn. In I Thessalonians 4:13, Paul instructs the people about grief: “Brothers, we do not want you to be ignorant about those who fall asleep (die), or to grieve like the rest of men who have no hope.” Paul does not tell them not to grieve; he says not to grieve as those who have no hope of eternal life.
Grief, then, is not wrong. It is a normal emotion just as love is a normal emotion. What often happens is that sorrow and grief mix up our priorities. We tend to put ourselves first, our loved one second and God last. That is the imbalance of grief.

Life and living after loss makes sense only when we reverse the order and put God first. Then we can experience His love and healing in our lives.

Grief is an individual experience. How each person deals with his loss depends on:
1. His past experience with loss, knowing himself, his coping mechanisms and how to use them
2. The value placed on the loss, how much did the person or thing mean to him?
3. The cultural, psychological, spiritual and family resources available to him to help him deal and cope with his loss

**Phases of the Normal Grief Response**

There are three phases involved in the normal grief response following the death of a loved one: shock and disbelief, disorganization and developing awareness, and reorganization and restitution.

**Shock and disbelief**

This stage is characterized by disequilibrium. The person who has suffered the loss functions automatically. Tears are common. Anger is also frequently a part of this initial response to death. The anger may be expressed outwardly toward another person, or it may be turned inward if he feels some responsibility for the person's death. This is particularly true if the death is unexpected.

There is a time of denial when the survivor does not want to acknowledge the loss and hopes there is some way to change the situation and recover the loss. This is often true during the time between death and the first viewing of the body of the deceased.

This is the time when guilt will be expressed: "If only I could have done more." The greater the survivor's ambivalence toward the person who died, the greater will be his feelings of guilt.

The most helpful thing for the nurse to do during this phase is to be available to listen. The survivor will have a need to talk particularly about the events leading up to the time of death. This is important and a normal part of grief. Do not offer too much conversation. Just sit or be available when needed.

It is also important to allow the family and significant others time to be with the deceased, especially in a hospital setting. This will give them opportunity to realize the reality of the death and provide time for them to say goodbye to the person they love. Allow them to touch and hold the body if they desire to do so and if this is possible. If they decide not to go to the room or to touch the dead person that should be permitted also. As nurses, we should be sensitive to the differences of individuals and accept their decisions. Just because it is something you would or would not do, does not make it right for others. Meet the needs of the family, not your own needs. If you do not have time to be with the family, call someone who does, e.g., the chaplain, supervisor, or another nurse.

You may have your own grief and loss to deal with if you have established a relationship with the dying person and his family.

There is nothing wrong with sharing that grief with the family as long as you are in control of your emotions. Tears often tell people that we are caring, compassionate human beings, that their loved one was important and valued. It also says we share in some small way the depth of their loss.

**Disorganization and developing awareness**

This phase begins when the survivor realizes his loss is permanent, that there is no chance for recovery. Despair sets in, and his behavior becomes increasingly disorganized and restless. He experiences extreme loneliness and often a sense of lost self-esteem. He may even experience identity problems if his life was dependent upon and closely intertwined with the person who died. This is particularly true for some women who have been married for a long period and lose their spouse. Much, if not most, of their identity has come from being "John's wife" or from being "Mrs. John Doe." Now that John is gone, so is the wife's identity.

If there has been time to prepare for his death, the widow may have had time to work through some of this loss of self-esteem and identity.

During this time, life is devoid of enthusiasm and social interaction is reduced. Feelings of helplessness are common, and frequently there is a sense of despair, which asks the questions: "Will my life ever be normal again? Will I ever get out of this dark hole that I am in?"

Symptoms of somatic stress may appear. Such things as insomnia, anorexia, lack of strength and exhaustion and sighing respirations are common in acute grief reactions.

The sensorium is generally altered and a preoccupation with the image of the deceased is experienced. It becomes critical not to forget one detail of his appearance. There may even be illusions when the survivor sees the deceased person. This is not abnormal. This is a part of the normal grief response. It is important to reassure the person that he is not "going crazy."

Spiritually the person may be so distressed he is unable to realize God's presence or activity in his life. He may be angry with God for taking the person he loved so much away from him. It is helpful to reassure him of God's love and active concern for him and for what is happening to him. When appropriate, prayer and scripture could be helpful in affirming God's presence and love.

**Reorganization and Restitution**

The person who survives and works through his grief begins to break the strong attachment to the deceased person. He no longer lives in the past with his memories but begins to establish new goals for his life. He does not forget the deceased person, but the person is no longer the focus of life. Relationships with others are restored and there is expansion of the social network. Life begins to take on meaning and purpose once more.

Not everyone goes through these phases in sequence or to the same extent. The person who is not in an identifiable stage is not necessarily maladapting. On the contrary, he may be coping and well adjusted to the changes that have occurred and to his loss.

There is no generally recognized specific time period for the completion of grief work. It is well documented, however, that survivors are at a high risk for stress related illnesses and even death for approximately one year following the death of someone they love.

**Abnormal Grief**

If grief work is not done, unresolved grief will surface later. Abnormal grieving does occur and has many faces, which may not be evident for some time after the loss or which may surface immediately. Some of the expressions of maladaptive grieving include the following:

1. Denial of the death — The survivor acts and talks as if the person were still alive. He may refuse to change certain rooms and insist on setting the table for the deceased as if he would be returning.
2. Use of vicarious objects to replace quickly the loss of the one he loves — A quick marriage to another person or focusing all his attention on a child or grandchild who reminds him of the deceased person is an example of this.
3. Delayed reaction — This delay in grief work is often signaled, persistent absence of any emotion. There is exaggerated use of the defense mechanisms of denial and suppression in an attempt to avoid the intense distress that comes from the loss. Because the person may internalize his grief, he is more susceptible to psychosomatic or stress-related illnesses such as ulcerative colitis, rheumatoid arthritis and asthma. There may be gross changes in behavior and emotions, which could result in such problems as severe depression, phobias or alcoholism.

4. Distorted reactions — These result from an exaggeration of grief. Such emotional responses include anxiety, fear, guilt, helplessness, anger and depression. These exaggerated feelings and emotions can lead to self-destructive behaviors. The person may attempt passive suicide by refusing to eat or over-indulging in food, alcohol, or drugs. On the other hand, he may attempt an active form of suicide and try to kill himself quickly. Another evidence of a distorted reaction to grief is the symptom/illness identification where the survivor takes on the symptoms of the deceased person’s illness.

5. Chronic grief — This is seen when any mention of the deceased evokes emotional responses after many years. These emotional responses are usually intense and unpredictable.

Again, it is important to realize that maladaptation and an abnormal grieving occur with different levels of intensity and severity. Maladaptation may occur for a short time and be eased with the love and caring concern of others or the sufferer may be so ill he requires hospitalization and intense therapy to help him work through his grief. It is important to be aware of the signs and symptoms of abnormal grief, but it is also important not to jump to conclusions and judge people if they are not responding just the way we think they should or as quickly as we think they should.

What can we do to intervene and facilitate normal grieving? Before a nurse can be actively involved, she must have an understanding of her own feelings and reactions to loss. She must know what she believes about life and death. She should know what her coping mechanisms are and what her limitations are. In this way, her own grief will not interfere with those she is trying to help in their time of grief.

When helping people who are confronted with loss and grief, we should allow them to express themselves in whatever way they choose. There are definite cultural differences that must be considered when talking about death and grief. Get to know what those cultural differences are for your own area of the country. Mourning rituals are different in various parts of the country and with different nationalities of people.

Be available to the survivors. Be a silent companion because your physical presence is much more important to them than your words of comfort.

Listen to them with empathy. Let them talk about the deceased person and the events leading up to his death. Answer questions for them about the death if they were not there when the death occurred. These facts are important and may help to ease guilt feelings for them.

Assist them in contacting their support people, particularly if they are alone at the time of the death. This may include such people as relatives, friends, or clergy. Make the phone calls for them whenever possible and appropriate.

Support them emotionally and help them start coping mechanisms. Help them understand that the intense emotions and feelings they may experience are normal and that they are not “going crazy.” It is important, however, to be sensitive to people who may be susceptible to abnormal grief and refer them for help and support from appropriate professionals whenever possible.

For the most part, nurses are involved with survivors only during the first phases of grief work and do not have the opportunity to follow them through the grieving process. However, this information is important because we may know people personally who are working through the grief process and because we may have patients we are working with who are ill because of unresolved grief or abnormal grief. This knowledge may help us provide better quality care for those we work with who are at some point in the grieving process. It also helps us to know when to talk with the physician about the possibility of making appropriate referrals for further professional intervention.

Summary

Working with the terminally ill is a demanding and emotionally draining job, particularly if we confront death daily. In what ways can we learn to cope with this stress so that we do not lose control of our emotions or “burn out” and leave the profession?

1. Get to know yourself. Identify your emotional strengths and limitations. Not everyone in nursing should work with the terminally ill. If you do not enjoy working with dying people or if you find yourself angry or depressed much of the time, you should seriously consider a change in your area of clinical practice.

2. Develop your own philosophy of life and death. As already discussed, knowing what you believe decreases inner anxiety and frustrations.

3. Build a support system both at work and at home. Find people who will listen and care about you and the grief you experience when people you care for die. Communicate your feelings and frustrations, but do not dwell on them. Develop hobbies that will help to release emotional energy.

4. Develop a sense of humor and use it. Learn to laugh at yourself and at life in appropriate ways. When working with terminally ill people on a daily basis it is easy to get morbid and cynical about life and death.

5. Education can be a great help to you. Learn about the needs of the dying and how to meet those needs. You will find that this decreases your anxiety and frustration levels because you will know better how to intervene and be helpful to those facing death.

There are no easy answers. Even with this information, death remains difficult for us. However, I want you to know that working and caring for the dying individual can be exciting and rewarding if we realize that, as nurses, we can do a lot to help people experience comfortable and peaceful death.
Suggested Readings

Aziz NM, Miller JL, Curtis JR., Palliative and end-of-life care research: embracing new opportunities. *Nurs Outlook*, Nov-Dec 2012, 60(6) p384-90


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