

End of Life I – Psychosocial Considerations

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Goals and Objectives

Course Description

"End of Life I – Psychosocial Considerations" is an asynchronous online continuing education course for occupational therapists and occupational therapy assistants. This course presents updated information about terminal illness and the last stages of life including sections on the terminal illness continuum, roles, communication, patient centered care, spirituality, advance care planning, goals of care, transitional care, care-giving, and psychosocial aspects of death and dying.

Course Rationale

The purpose of this course is to present occupational therapists and occupational therapy assistants with current information about the psychosocial issues relating to death and dying. A greater understanding of death and dying will enable occupational therapists and occupational therapist assistants to provide more effective and efficient care to individuals affected by terminal illness.

Course Goals and Objectives

Upon completion of this course, the participants will be able to:

1. differentiate the phases of the task-based model of life-threatening illness
2. identify the different dying trajectory patterns.
3. identify key components and skills necessary to facilitate effective communication.
4. demonstrate an understanding of patient-centered care.
5. define and differentiate between spirituality and religion
6. identify and define the key components of advance care planning.
7. define the parameters for determining decision making competency.
8. list the goals of care for each stage of terminal illness
9. list the duties and responsibilities of caregivers.
10. define and differentiate between loss, grief, bereavement, and mourning.
11. Identify the ways in which children experience loss differently from adults
12. identify differing cultural responses to death.

Course Provider – Innovative Educational Services

Provider Contact Information – information@cheapceus.com

Course Instructor – Michael Niss, DPT

Financial/Non-financial Disclosure - Neither the Provider nor the instructor have any financial or non-financial conflict of interest related to the presentation of this CE program.

Target Audience – Occupational Therapists, Occupational Therapy Assistants

OT Scope of Practice – Foundational knowledge

Course Educational Level – This course is applicable for introductory learners.

Course Prerequisites – None

Method of Instruction – Distance Learning – Independent; Asynchronous online home study

Location - Cheapceus.com

Date – Continuously available on-demand

Course Completion Requirements / Criteria for Issuance of CE Credits – Completion of instructional materials and a score of 70% or greater on the course post-test.

Continuing Education Credits – Four (4) contact hours / .4 AOTA CEUs

Course Fee - \$39.95

Registration Information – No pre-registration required; available on-demand at Cheapceus.com

Special Needs Requests – Email: information@cheapceus.com or phone: 954-663-4101

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End of Life I – Psychosocial Considerations
Course Outline

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Course Outline	
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Terminal Illness Continuum	
Diagnosis	
Treatment	0:30
Remission	
Recurrence	
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Overview

From the moment there is a confirmed diagnosis of terminal illness, the patient and family will be confronted with levels of complexity and distress that will change them forever. From this traumatic event onward, the person becomes a patient, and enters an uncertain world where he or she will be challenged in ways that may be profoundly threatening and foreign. The ability to face challenges with courage is deeply ingrained in the human spirit, and enables the patient to focus fear into meaningful activity.

Patient Response

Although it seems odd to think of dying patients as survivors, in fact, the needs and concerns of the dying are quite similar to anyone with a chronic disease: Will I be treated with physical, social, and spiritual respect, be involved in decision making, be able to make a meaningful contribution, and receive the best medical care possible to maintain my quality of life and my connections to those I love?

The meaning patients give to being told that they are going to die will have the greatest impact on how they manage this reality. Older patients will generally manifest less distress than younger patients. For most people, dying is an exaggeration of how they have lived. Very few transformations occur at the end-of-life.

Loss is most acute and is magnified when patients are aware that they are dying. Many powerful emotions are stirred up as the patient and family begin to actively mourn their impending losses. In addition to grieving for relationships that are actually being lost, patients also mourn the loss of potential relationships that did not in the past, or will not in the future, come to fruition. For some people this can be the hardest part of letting go.

The accumulated physical and psychosocial losses caused by the disease, treatment, and expenditure of family resources are superimposed on the normal aging process. It is normal for dying individuals to question the usefulness of all they have been through when they are dying in spite of it. There is also guilt and shame about the burden placed on loved ones. For the family, it is helpful to know that they did all that was possible. Anger is common as dreams and aspirations for the future are now thwarted.

For those who have lived deeply meaningful lives or have a world view of the next life as transcendent, death may be seen as a reward and extremely comforting. The dying patient may hold opposing viewpoints simultaneously. Dying is a process of peripheral vision for most people, and this seems to work. Most people look at death the same way you look at the sun: indirectly and fleetingly. This can be disconcerting to health care professionals who prefer clarity and may easily misconstrue the patient's peeks at his or her demise as

denial. This is not denial; it is simply a human being trying to make sense of the ambiguity of life. Most dying people have some view of what will happen to them after they die. To find out you must take the time to ask, frequently, and more than once.

For those people who are very controlling, have lived a life of fear and anger, who have many regrets because they have led spiritless lives, have hurt others, and are alone due to their own behaviors, this disconnectedness and unfinished business may cause significant distress. This will be a hard death. These patients should be referred to a mental health professional or for pastoral counseling.

When patients are told that their disease will significantly shorten their lives, there is a period of disbelief and shock, and a series of questions will emerge:

- Is there something else to be done that we have not tried?
- When am I going to die? What, if any, control do I have over the process of dying? How will I die?
- Will it hurt? Why me; why now? What will be the impact on my family? Will I be abandoned? How will I be remembered?
- Are my affairs in order? Have I been a good person? What is left to be done?
- How do I cope with waiting?

Patients should be encouraged to realize that these questions are still in play and that they still have some control and influence over at least some of their concerns. No person does well in life when he or she is adrift. Dying persons have worth and the ongoing responsibility to make a contribution beyond their past on many levels, including how they teach the next generation to die in a meaningful way, to resolve conflicts with loved ones, to demonstrate love for others and accept love in the manner it is offered, to make amends for wrongs done to others, to work with their health care team to manage symptoms and their dying process, to have their personal and legal affairs in order, to leave clear instructions about advance directives, to accept the reality of what they cannot change, to share their sense of loss and loving with significant others by allowing them to participate in this final shared ritual, to be grateful for the gift of life they have received, and to find a sanctuary in their sense of the universe and their unique place within it.

Survivor Goals for Dying Patients

The survival goals for the dying patient are:

- to be treated with dignity and respect while surrounded by loved ones

- make a contribution to their community
- control their emotional responses, especially fear
- make meaning of their ongoing experience
- receive the best medical and psychosocial care possible until they die.

Model of Life-Threatening Illness

Although several models attempt to account for how individuals cope with a life-threatening illness, the task-based approach is the model most commonly used. Several significant, limiting factors have been ascribed to the older model, a stage theory based on the original work of Elizabeth Kubler-Ross, including the actual existence of these five stages (denial, anger, bargaining, depression, and acceptance). There is no evidence that all individuals experience these stages or that movement from one stage to another occurs sequentially.

The task-based model does not imply any order or sequence and is therefore viewed as a more flexible, fluid model that helps to empower the patient and his or her family and significant others. Four phases, or segments, of a life-threatening illness have been identified: prediagnostic, acute, chronic, and recovery or death. A task-based concept has been applied to explain how individuals confront each phase.

Prediagnostic Phase - The prediagnostic phase of a life-threatening illness is the time before the diagnosis of illness during which an individual recognizes symptoms or risk factors that make him or her prone to illness and during which diagnostic studies are performed. This is not a single moment but may culminate in one moment when the diagnosis is first spoken.

Acute Phase - The acute phase centers on the crisis of diagnosis in which a person is forced to understand the diagnosis and make a series of decisions regarding his or her medical care.

Chronic Phase - The chronic phase of an illness is the period of time between the diagnosis and outcome. Individuals attempt to cope with the demands of life while simultaneously striving to comply with treatments and deal with side effects.

Recovery - Persons may experience recovery from their disease and thus deal with the psychological, social, physical, spiritual, and financial after-effects of their illness.

Terminal Phase - Other individuals encounter a final phase, or terminal phase, of illness when death is no longer just possible but is inevitable. At this time, medical goals change from curing illness or prolonging life to providing comfort

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and focusing on palliative care. The tasks during this final phase reflect this transition and often focus on spiritual and existential concerns.

Terminal Illness Continuum

The terminal illness continuum is composed of a series of often predictable events experienced by patients. The categories are divided into diagnosis, treatment, remission, recurrence or progression, advanced disease, and care at the end-of-life. Any illness-related event is experienced as stressful to the patient. Although the etiology of psychosocial distress shifts over time and is triggered by different challenges relating to the specific phase, most patients will experience a sense of dread, feel trapped, experience fear, and feel a lack of control and predictability, frustration, and anger. Depression (10% prevalence in Americans over the course of a lifetime and increases to 15 to 25% in people with cancer at some time during their illness) is closely linked to poorly managed symptoms and advancing disease. Although there is significant confusion relating to depression in terminal patients, clinical depression, unlike sadness and frustration, is never normal and should always be treated.

Diagnosis

Patient response: At diagnosis, the patient is initially numb and traumatized while trying to integrate new information and defining next steps. Finding health care providers, figuring out insurance coverage, and shifting family responsibilities are the first steps toward trying to stabilize the environment. Fear, anxiety, denial, confusion, terror, and an assault on the sense of self are common. Rapidly shifting focus between hope of a rapid cure and thoughts of dying are to be expected. This acute period of disequilibrium generally lasts about 7-14 days.

Patient goals: The goal of the patient at diagnosis is to find the best medical care possible while minimizing disruption to life.

Clinician's' contribution to goals: A clearly defined plan of action, availability, and emotional support are what the newly diagnosed patient needs most. Being available means providing information, explanation and re-explanation, support, resources, and referrals, if requested. The health care professional can help the patient focus on next steps, which will help focus the energy of the emotional reactions. For those patients who cannot get focused on next steps after a reasonable amount of time (5-7 days), a mental health referral should be considered.

Treatment

Patient response: Treatments for many illnesses have significantly improved in the last 25 years. For example, surgeries have become less disfiguring, radiation therapy doses have decreased, and the side effects of chemotherapy are much better managed. However, many patients still say that coping with treatment is harder than coping with the reality of having a disease.

Patient goals: The goal of the patient during treatment is primarily to complete treatment. Other goals are to maintain as much independence as possible by continuing to work, staying insured, coping with side effects, and keeping family life as normal as possible.

Clinician's contribution to goals: Provide a clear plan of action-what will happen, when, by whom. Describe who to contact if there are problems or questions, especially after hours. Anticipate and work to minimize the unpleasant side effects of treatment. Support the patient's optimism and perseverance. Prospectively provide a tailored list of written resources (i.e., transportation, financial assistance) and referral information for psychosocial support (i.e., names of counselors, peer support groups in the area, cognitive behavioral coping skills training). Any patient who cannot tolerate treatment due to psychosocial distress should be referred to a mental health professional immediately.

Remission

Patient response: A patient's response to remission is usually one of having a second chance. The patient feels like he or she has dodged a bullet and is grateful. A positive attitude, prayer, diet, and many other beliefs and behaviors will also be thought to have contributed to the remission. A sense of control and exhausted relief will be experienced. This may also become a time of reviewing one's life. Strong relationships are usually strengthened at this time, while weak ones may disintegrate. Remission is both a time of relief but also a time when there is a fear of jinxing the delicate and precious victory just experienced. Hypervigilance and some degree of hypochondriasis are to be expected. The further patients get from treatment, the more their distress will decrease. If distress does not decrease over time, intervention is required.

Patient goals: The goal of the patient at remission is to redefine what a normal life is for them now, given their illness experience. Psychosocial rehabilitation is central to this effort. Fear of recurrence is a shadow on every victory. Reinvesting in work and family life is essential, as there is a weaning process from the health care system. It is a challenge for the individual to cope with inevitable changes within the family structure and social network, to resume intimacy with their loved ones, and most of all to give some meaning to their experience as part of a life still being lived.

Clinician's contribution to goals: Celebrating remission and managing fear of recurrence are always concerns for patients, and health care providers can help the patient focus on the future and lay out next steps. By maintaining a scheduled set of visits, patients' anxiety about separation from the person who treated them will be reduced significantly. About 2 months after treatment is completed, the full impact of physical changes, vulnerability, and what was just experienced may be manifested similarly to the emotional response at the time of the original diagnosis. This is to be expected. A referral should be made to a peer support group if available. If the distress response is prolonged or highly disturbing to the patient or family, a timely referral should be made to a mental health professional. If present, depression should also be assessed by a mental health professional.

Recurrence or Progression

Patient response: The personal meaning given to recurrence or advancing disease will greatly influence the response to the deteriorating situation. Generally, patients will need time to digest and integrate the implications of recurrence or advancing disease. As a result of the patient's physical condition and poorer prognosis, anger, frustration, anxiety, depression, and demoralization are common experiences. Guilt and shame may also be present as patients may feel some responsibility for what is happening to them. They may feel that they have let down their family and their health care providers. Lack of control, e.g. fears about physical deterioration and death will surface. Concerns about the impact on loved ones will be significant. Intellectual constructs about the end-of-life may shift and be undermined as the potential of death becomes more of a reality. Spiritual belief systems may be challenged or strengthened. Some patients will get angry at the disease and take a combative and heroic stance against it.

The family may be in crisis as they are forced to seriously consider life without the loved one. For the first time, the needs of the patient and the needs of the family may diverge. Unrelieved physical symptoms will increase suffering and psychosocial distress and only heighten the sense of losing control. It is normal for patients to have fleeting or periodic thoughts of taking control by ending their own lives. Patients who dwell on suicide or have specific plans should be referred for a psychiatric assessment as soon as possible.

Patient goals: The goal of patients within the context of recurrence or advancing disease is to maximize a sense of personal control by understanding the illness experience within the overall context of their lives, i.e. to control the disease and to make conscious choices about further treatments (second-line treatments and clinical trials) and to consider where their time and resources are going to be invested. Realignment of relationships also gains importance as time is seen as more precious; and family and close friends declare their level of commitment in practical and emotional ways. Patients at this stage are often focusing

considerable energy on coping with the chronicity of the disease and the uncertainty of the outcome of additional treatment within the context of continuing to contribute at home and at work.

Clinician's contribution to goals: Recurrence and advancing disease are marked by the patient's experience that the "last shoe has dropped."

At recurrence of advancing disease, it is important that the patient be reassured that it is the treatment that has failed, not the patient or the health care providers. When the limits of human capacity are openly acknowledged, there is the potential for a deeper human connection between the patient and clinicians.

The health care providers can best support the survivor's goals by clearly delineating the next steps, outlining a plan of action to manage the medical challenges, and communicating to the patient that he or she will never be abandoned. Information, hope, and support are what the patient especially needs at this point. The health care team should support the patient's efforts to communicate honestly with the family. A family meeting is strongly suggested. In addition to referral to a peer support group, a referral to a mental health professional should also be offered.

If the concept has not already been introduced, it is essential at this point to describe the benefits of hospice: an interdisciplinary team, experts in symptom management, psychosocial and spiritual support, and the fact that the benefit is covered by Medicare. It is also important that you tell the patient and family that you will remain actively involved and that the emphasis may shift, but you are still invested and care about the outcome.

The Dying Trajectory

Individuals who are dying do not move toward death at the same rates or in the same ways. Different causes of death are associated with different patterns of dying. These patterns, referred to as dying trajectories, indicate the path of an individual's experience of dying. The attitudes and behaviors of people caring for the patient are strongly influenced by their perceptions of the patient's dying trajectory. Trajectories will also affect the types of emotional responses and coping mechanisms displayed by patients and their families, as well as the interventions that will be initiated. For these reasons, the purpose of understanding one's dying trajectory is to anticipate and implement appropriate interventions. Uncertain trajectories are more difficult to cope with than are certain trajectories because ambiguity generates anxiety.

The dying process can be described in terms of duration and shape. Duration refers to the time between the onset of dying and the arrival of death. Shape designates the course of the dying process (i.e., whether one can predict how the

process will advance and whether the approximate timing of the death is expected or unexpected).

The following examples of trajectories have been described:

- The **gradual slant** is characterized by a long, slow decline, sometimes lasting a period of years.
- The **downward slant** is represented by a rapid decline toward death in which the chronic phase of the illness is either short or nonexistent.
- The **peaks and valleys** trajectory is marked by alternating patterns of remission and relapse.
- The **descending plateaus** trajectory is indicated by long, slow periods of decline followed by restabilization. Patients in this trajectory must repeatedly adjust to different levels of functioning.

Deaths associated with cancer and certain neurological conditions are often lengthy processes and may be linked with long-term pain and suffering and/or a loss of control over one's body or mental faculties. Protracted deaths are more likely to drain a family's physical and emotional resources because caregivers are required to provide care for longer periods of time. The spectrum of chronic care needs of these patients and their caregivers may benefit from referral to a palliative care service, which may provide resources more appropriate to their needs than those provided by the more cure-centered focus of high-tech medical facilities. In one Italian study (Rossi; 2004) of caregivers of home-treated patients with advanced cancer, bereavement maladjustment problems at 12 months after a patient's death correlated with self-reports of emotional distress and with caregiving-related problems detected at the time of referral to the palliative care unit home care program. Identification of such predictors may facilitate the development of interventions for at-risk individuals.

Roles

Less tangible, and often very difficult, is the loss of social role that illness can bring. Children temporarily or permanently stop attending school. Adults may lose their jobs. A patient may become less functional in a family role, as a parent, child, or sibling. There can be losses, too, in the patient's role in the community, as an active church member, welcoming host, proud gardener, or other group participant.

The Sick Role and the Caregiver Role

In place of established roles, patients may take on the "sick" role and family members the "caregiver" role with varying degrees of personality fit for those

roles. Transitions into these new roles may develop slowly or rapidly, with varying mixes of earlier roles and varying degrees of resistance and expectations of role definitions.

In the sick role, the ill person may take on an identity of being dependent. He or she expects and is expected to be cared for by others who tend to needs that he or she cannot fulfill alone. Family members may adopt different caregiving activities and corresponding identities as they settle into expectations for the activities and resulting relationships.

Role transitions can be difficult. For instance, as the patient becomes unable to perform activities of daily living, the caregiver must learn how to help with personal function. This type of intimacy may not be welcome, involving as it does different self-images and relational boundaries. A sense of loss for one's former self may exist for the patient and the caregiver. It may be necessary for each party to experiment with various ways of performing the roles.

The healthcare professional can help by acknowledging and normalizing the attention these transitions need, emphasizing that they do not always go smoothly and may require the types of relational coping skills that family members have found helpful in other stressful adaptations.

With adjustment, the caregiving role can yield gratification. It can also be accompanied by significant burdens. Caregivers often experience worse health outcomes than their matched counterparts.

The Dying Role and Successor Roles

Society assigns a different role for people who are expected to die soon. They are no longer expected to struggle for cure and recovery. They are encouraged to reach a peaceful state with others and offer parting gestures. They are expected to reach some type of conclusion to their life story or personal legacy. They may be encouraged to make practical arrangements for material gifts and sometimes for their own death-related events, such as a funeral. They may be expected to offer designations for successors to the roles they have held in their lifetime, such as asking a child to "look after mother for me" or a friend to "see to the finances for my child."

As the patient enters the dying role, family members, friends, and colleagues begin to take on the role of successors. They accept the role of guarding the person's personal and material legacies, sometimes finishing an unfinished project or recording the dying person's story so that it can be passed down through the generations.

Role Transitions

Although important, new roles can be detrimental if they are entered prematurely. Patients can feel discarded before their time, and future caregivers or successors can feel that they have made serious errors in a role they cared deeply about. Patients and families can be encouraged to settle their differences when possible and to enjoy the peace that results. Suggestions can be offered about making practical arrangements early, with the explicit acknowledgement that it is intended to "get them squared away," rather than to usher in an expected death. The notion of planning for the eventuality while living for quality relationships can be helpful. Preparations for the future may be especially helpful for close caregivers, who may have difficulty with transitioning out of an all-consuming role.

Relationships

Along with changing social roles, personal relationships are often in transition. Personal needs change. Capacities for relating in previously habitual ways change. The patient can feel abandoned when it emerges that his or her significant other is not well-suited to the caregiver role. The family member can feel abandoned when it emerges that the patient can no longer perform in the ways he or she did in the past. Sexual drive and capacity may change, and the meaning and emotional needs associated with it may change. Favorite recipes may taste different, taking away the gratifications of cooking and eating together. The bathroom, bedroom, and living areas may be transformed by medical equipment that reminds people of sickness or death.

Communication

Communicating information, whether it is good or bad news, is an essential skill for healthcare professionals. Many find it challenging to communicate effectively, especially when it involves an illness from which the patient may eventually die. Some feel inadequately prepared or inexperienced. Others fear the news will be so distressing as to adversely affect the patient, family, therapeutic relationship, or course of the business day.

However, the vast majority of Americans want to know if they have a life-threatening illness. Although legitimate cultural variations are important, communicating in a direct and compassionate manner improves the patient's and family's ability to plan and cope, encourages realistic goals and autonomy, supports the patient emotionally, strengthens the physician-patient relationship, and fosters collaboration among the patient, family, physicians, and other professionals.

Health care professionals frequently encounter patients who expect their problem to be “fixed.” They hope that their illness will go away and never come back. They seem to want the doctor to tell them that the disease can be cured, even if the physician knows it is unlikely or impossible. Doctors may also notice that they want to tell patients what they want to hear.

Clinicians' responses to this need for hope can have unfortunate consequences. They may talk in language that can easily be misinterpreted by patients. For example, the doctor may say “there is a 40% chance of response,” and the patient may hear, “there is a 40% chance of cure.” Often, healthcare professionals do not explore patients' understanding about what this really means because they feel that enough bad news has already been conveyed.

Language Barriers

The assistance of an experienced translator who understands medical terminology and is comfortable translating bad news is sometimes required.

If possible, avoid using family members as primary translators. It confuses their roles in the family unit and may raise issues of confidentiality. Additionally, family members may not know how to translate the medical concepts and/or they may modify the news to protect the patient. Instead, when family members are present who do speak both languages, ask them to supplement the primary translation and support the patient and other members of the family.

When working with a translator, sit in a triangular arrangement so that you can face and speak directly to the patient, yet still turn to look at the translator. Speak in short segments, and then give the translator time to convey the information. Verify the patient's and family's understanding and check for an emotional response.

Communication Skills

Communication with the patient and family entails a number of essential skills, which can be remembered as five E's:

- **E**ngaging the patient.
- **E**liciting the patient's understanding/current concerns.
- **E**ducating the patient.
- **A**ddressing **E**motions.
- **E**nlisting the collaboration of the patient and caregiver.

These skills serve the purpose of developing rapport; establishing patient understanding of their condition and important concerns; providing information about the illness and treatment; responding to emotions using empathic,

validating, and clarifying responses; and enlisting the patient and family in the treatment plan.

Clinicians should remember that many patients are anxious about medical visits. Putting patients at ease will allow better assimilation of information; and the skills of inquiring about the patient's point of view, listening without interrupting, and being empathic will be perceived as supportive and caring. As one study (Frankel; 2001) found, the first few moments of the interaction are especially important in forming lasting impressions; a friendly handshake and making eye contact are important first steps in creating trust and rapport. Sitting down puts the health care provider at patient eye level and invites discussion rather than one-way conversation; asking the names and relationships of others in the room acknowledges their potential role as allies in the care of the patient. Inquiring briefly about the patient's hometown, family, or other personal aspects of life, helps shift the focus from patienthood to personhood. Not interrupting while patients are talking and acknowledging the importance of their concerns conveys respect for their point of view.

Patients will generally feel much better if they are confident that you will:

- Listen to their concerns.
- Expect them to tell you what and how much information they need to know about their illness.
- Assure them that there is always something that can be done to maximize their function and comfort.
- Be there for them for as long as they require your services, and not abandon them.
- Strive for exquisite management of their physical and psychosocial symptoms at all times and that you expect they will actively participate in agreed-upon plans of care.
- Offer all applicable options for adequate symptom management, including palliative sedation, should this become necessary.
- Actively involve them and others they identify in ALL appropriate decision making around their care.
- Not remind them that they are dying at every visit, but acknowledge that at present there is no effective way to cure them and that their lives will be shortened by their disease.
- Inform them of any new advances that could potentially help them.
- Remind them that they always have something to give back (even if it is to teach the next generation how to end a life) and that you will help them to get the support they need to do so.

- Refer them to other health care professionals when appropriate or when they ask, such as other medical specialists (e.g., palliative medicine specialists), social workers, psychologists, psychiatrists, chaplains, etc., as appropriate.
- Encourage them to remember that life is a precious and fleeting gift that needs to be lived to the fullest regardless of the circumstances and that you will do your part to make that happen by providing excellent medical care, timely referral, and emotional support.

Patient-Centered Care

The patient-centered model of care emphasizes the importance of the clinician's relationship with the patient and the patient's family as a therapeutic tool, endorses shared decision making as a key component of treatment, and emphasizes clinician understanding and addressing of patient concerns and information needs as important in promoting patient well-being and quality of life. Interpersonal and communication skills are essential in achieving these goals and are also associated with other important clinical outcomes for the patient, the patient's family, and the medical team. These skills are especially important in highly charged emotional situations such as transitioning the patient to palliative care and at the end of life.

Patient Information Needs

Imparting information to the patient serves a number of key functions: it grants patients a sense of control, and it can reduce anxiety, improve compliance, create realistic expectations, promote self-care and participation, and generate feelings of safety and security. Many patients actively seek information and identify acquiring information as a priority. In one study by Butow; with 12 specific information and support topics listed, patients chose information as their greatest need. Ninety-seven percent of patients wanted more feedback on the progress of the cancer, 88% wanted more information on the probable future of their illness, and 91% wanted more information about their illness. Another study by Lobb found that 83% of the breast cancer patients interviewed wanted as much information as possible, 16% wanted limited information, and 91% of women wanted to know their prognosis before beginning adjuvant treatment; 63% wanted their oncologist to ask them whether they wanted to know their prognosis. Patient needs may, however, shift to an emphasis on support immediately after the first consultation. Another study by Butow has shown that 63% of patients also wanted more assurance that they would be looked after, 59% wished for greater reassurance and hope, and 59% expressed an increased need to talk about their worries and fears.

Although many patients have high information needs, some patients want less information about their illness. Research increasingly supports clinical experience

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in clarifying that patients differ in the amount of information they want and need about their care. In addition, patients' information needs may change at different points on the disease and treatment trajectory, with patients who have advanced disease desiring less information about their illness. It is often difficult for providers to accurately estimate or provide the amount or type of information that patients want, leading to patient dissatisfaction with the amount or type of information they receive. Thus, it is important for a clinician to ask how much information a patient wants.

Research has attempted to characterize different information styles in a variety of ways. One of these is monitoring and blunting. Monitors actively seek information, whereas blunters avoid or distract themselves from information. For example, one study by Ong found that having a monitoring style was related to a preference for detailed information, participation in medical decision making, and patient question-asking. Thus, patient information style may greatly affect patient communication preferences and patient interactions with health care providers. This area warrants additional study and has implications for how patients adjust to their illness experience.

Participation Styles

Participation style in decision making represents how much patients want to be involved in the decision-making process related to their care. Studies of patient desire to participate in treatment decisions have yielded conflicting results, largely depending on how participation in decision making is defined.

Participation can range from the patient actively engaging in the decision-making process, to the patient wanting the doctor to make the ultimate decision. The desire to participate in treatment decisions is associated with locus of control, which describes how an individual tends to attribute control. Patients with an internal locus of control seek information to control their own destinies, whereas those with an external locus of control tend to passively accept their lot.

Because research shows that a range of patient decision making exists, increasing participation for all patients may not be the most effective strategy. One study in 1993 by Pierce categorized patients with early-stage breast cancer into the following groups:

- Delayers, who consider at least two options, but their deliberation is perfunctory and they immediately prefer one option.
- Deferrers, who accept their doctors' recommendations without a significant degree of reflection.

- Deliberators, who weigh the pros and cons of each treatment and do not make a choice until they have considered all the relevant information and have found an alternative with which they are satisfied.

McVea identified four patterns to describe how patients' emotional styles affected treatment decision making. These styles were labeled passive, avoidant, panicked, and rational. Passive decision makers allowed directive physicians to make treatment choices for them. They responded more to the caring attitude of their provider and the need to have someone to believe in rather than to an opportunity for autonomous decision making. Women with breast cancer using an avoidant style of decision making refused to actively confront their diagnosis or participate in planning their cancer treatment. Panicked patients were so fearful when confronted with a diagnosis of cancer that they could not participate in decision making, whereas rational decision makers were able to control strong feelings of fear and engage fully in decision making.

Although the categorization of patients into various participation styles appears to offer some useful predictive power for defining communication patterns, the issues are complex. It has been suggested that to match the provision of information and support with the expressed needs of patients, patients should ideally be queried frequently about their needs. Information and involvement preferences may also be responsive to factors such as changing disease status and the behavior of the physician during consultation. Individualizing treatment discussions to patients' preferred decision-making styles rather than encouraging decision-making autonomy is likely to maximize outcomes for patients with life threatening illness.

Spirituality

National surveys consistently support the idea that religion and spirituality are important to most individuals in the general population. More than 90% of adults express a belief in God, and slightly more than 70% of individuals surveyed identified religion as one of the most important influences in their lives. Yet even widely held beliefs, such as survival of the soul after death or a belief in miracles, vary substantially by gender, education, and ethnicity. Both patients and family caregivers commonly rely on spirituality and religion to help them deal with serious physical illnesses, expressing a desire to have specific spiritual and religious needs and concerns acknowledged or addressed by medical staff; these needs, although widespread, may take different forms between and within cultural and religious traditions. A survey of hospital inpatients found that 77% of patients reported that physicians should take patients' spiritual needs into consideration, and 37% wanted physicians to address religious beliefs more frequently.

Paying attention to the religious or spiritual beliefs of seriously ill patients has a long tradition within inpatient medical environments. Addressing such issues has been viewed as the domain of hospital chaplains or a patient's own religious leader. In this context, systematic assessment has usually been limited to identifying a patient's religious preference; responsibility for management of apparent spiritual distress has been focused on referring patients to the chaplain service.

Interest in and recognition of the function of religious and spiritual coping in adjustment to serious illness has been growing. The development of better assessment tools will make it easier to discern which aspects of religious and spiritual coping may be important in a particular patient's adjustment to illness. Of equal importance is the consideration of how and when to address religion and spirituality with patients and the best ways to do so in different medical environments. Although addressing spiritual concerns is often considered an end-of-life issue, such concerns may arise at any time after diagnosis.

Definitions

Specific religious beliefs and practices should be distinguished from the idea of a universal capacity for spiritual and religious experiences. Although this distinction may not be salient or important on a personal basis, it is important conceptually for understanding various aspects of evaluation and the role of different beliefs, practices, and experiences in coping with cancer.

The most useful general distinction to make in this context is between religion and spirituality. There is no general agreement on definitions of either term, but there is general agreement on the usefulness of this distinction. Religion can be viewed as a specific set of beliefs and practices associated with a recognized religion or denomination. Spirituality is generally recognized as encompassing experiential aspects, whether related to engaging in religious practices or to acknowledging a general sense of peace and connectedness. The concept of spirituality is found in all cultures and is often considered to encompass a search for ultimate meaning through religion or other paths.

Religion is highly culturally determined; spirituality is considered a universal human capacity, usually—but not necessarily—associated with and expressed in religious practice. Most individuals consider themselves both spiritual and religious; some may consider themselves religious but not spiritual. Others, including some atheists or agnostics, may consider themselves spiritual but not religious.

Spirituality and spiritual well-being are more challenging to define. Some definitions limit spirituality to mean profound mystical experiences; however, in considerations of effects on health and psychological well-being, the more helpful definitions focus on accessible feelings, such as a sense of inner peace,

existential meaning, and purpose in life, or awe when walking in nature. For the purposes of this discussion, it is assumed that there is a continuum of meaningful spiritual experiences, from the common and accessible to the extraordinary and transformative. Both type and intensity of experience may vary. Other aspects of spirituality that have been identified by those working with medical patients include a sense of meaning and peace, a sense of faith, and a sense of connectedness to others or to God.

The definition of acute spiritual distress must be considered separately. Spiritual distress may result from the belief that illness reflects punishment by God or may accompany a preoccupation with the question “Why me?” A patient may also suffer a loss of faith. Although many individuals may have such thoughts at some time following diagnosis, only a few individuals become obsessed with these thoughts or score high on a general measure of religious and spiritual distress .

Hospital Chaplains

Traditional means of providing assistance to patients has generally been through the services of hospital chaplains. Hospital chaplains can play a key role in addressing spiritual and religious issues; chaplains are trained to work with a wide range of issues as they arise for medical patients and to be sensitive to the diverse beliefs and concerns that patients may have. Chaplains are generally available in large medical centers, but they may not be available in smaller hospitals on a reliable basis. Chaplains are rarely available in the outpatient settings where most care is now delivered.

Support Groups

Support groups may provide a setting in which patients may explore spiritual concerns. If spiritual concerns are important to a patient, the health care provider may need to identify whether a locally available group addresses these issues. The published data on the specific effects of support groups on assisting with spiritual concerns is relatively sparse, partly because this aspect of adjustment has not been systematically evaluated.

Health Care Providers’ Role

Spirituality, religion, death, and dying may be experienced by many providers as a taboo subject. The meaning of illness and the possibility of death are often difficult to address. The assessment resources noted above may be of value in introducing the topic of spiritual concerns, death, and dying to a patient in a supportive manner. In addition, reading clinical accounts by other health care providers can be very helpful. One such example is a qualitative study by Sinclair utilizing an autoethnographic approach to explore spirituality in members of an interdisciplinary palliative care team. Findings from this work yielded a collective spirituality that emerged from the common goals, values, and belonging, shared

by team members. Reflections of the participants offer insights into patient care for other health care professionals.

Advance Care Planning

Advance care planning is a process, not an event. It is the process of planning for future medical care in the event that the patient is unable to make his or her own decisions. During this process patients explore, discuss, articulate, and document their preferences. The process helps patients identify and clarify their personal values and goals about health and medical treatment. They identify the care they would like, or not like, to receive in various situations. Patients also determine who should make health care decisions on their behalf in the event that they cannot make decisions for themselves.

Ideally, advance care planning is a process of structured discussion and documentation woven into the usual process of care that is reviewed and updated on a regular basis. It is designed to ensure that a patient's wishes will be respected in the event that the patient is unable to participate in decision making. In the case of a pediatric patient, it is designed to ensure that the patient's parents are provided with an understandable discussion of the child's prognosis and treatment options, should the child's condition deteriorate to a terminal state. The sense of control and peace of mind that this process fosters in the patient and the reduction in anxiety of proxy decision makers are important benefits.

Advance care planning is important for many reasons. Patients have a right to participate in the planning of their health care. Health care providers have a legal and professional responsibility to assure this, even if the patient loses the capacity to make decisions. The process of determining those preferences for treatment builds trust and a sense of teamwork between the patient, the proxy, and the clinical professionals in several ways. The invitation to discuss future care permits the patient (or the parents if the patient is a child) to understand his or her own values, goals, and preferences that govern his or her life. The health care team and proxy learn about those preferences and needs. The process helps to relieve anxieties and fears on both sides because a spirit of frankness and openness is fostered. Advance care planning is preventive medicine because it avoids future confusion and conflict.

The model for advance care planning can be applied to other decision-making processes as patients plan for the end of their lives (e.g., planning for bequests, autopsy, burial/cremation, funeral/memorial services, guardianship, choices of caregivers, and settings for care).

Advance Directives

Advance directives are prior directives from the patient for his or her health care. Advance directives fall into two categories: those that have to do with instructions for medical care and those that have to do with designating a proxy for the patient. Instructional directives for care can be recorded in a variety of documents.

Advance directives are the legal documents, such as the living will, durable power of attorney and health care proxy, which allow people to convey their decisions about end-of-life care ahead of time. Advance directives provide a way for patients to communicate their wishes to family, friends, and health care professionals and to avoid confusion later on, should they become unable to do so.

Ideally, the process of discussing and writing advance directives should be ongoing, rather than a single event. Advance directives can be modified as a patient's situation changes. Even after advance directives have been signed, patients can change their minds at any time.

Complex choices about end-of-life care are difficult even when people are well. If a person is seriously ill, these decisions can seem overwhelming. But patients should keep in mind that avoiding these decisions when they are well will only place a heavier burden on them and their loved ones later on. Communicating wishes about end-of-life care will ensure that people with terminal illness face the end of their lives with dignity and with the same values by which they have lived.

Wills

A will is important so that patients can give instructions about distribution of their money and property when they die. Patients can name a trusted family member, friend, or professional to handle their personal affairs (also known as an Executor). It is advisable to seek the expert advice of a lawyer in drawing up a will so that the decisions made about taxes, beneficiaries, and asset distribution will be legally binding. This process can relieve a patient's family and friends of an enormous burden in case of disputes or questions about allocation of the patient's assets.

Living Will

A living will is a set of instructions documenting a person's wishes about medical care intended to sustain life. It is used if a patient becomes terminally ill, incapacitated, or unable to communicate or make decisions. Everyone has the right to accept or refuse medical care. A living will protects the patient's rights and removes the burden for making decisions from family, friends, and physicians.

There are many types of life-sustaining care that should be taken into consideration when drafting a living will. These include:

- The use of life-sustaining equipment (dialysis machines, ventilators, and respirators);
- "Do not resuscitate" orders; that is, instructions not to use CPR if breathing or heartbeat stops;
- Artificial hydration and nutrition (tube feeding);
- Withholding of food and fluids;
- Palliative/comfort care; and
- Organ and tissue donation.

It is also important to understand that a decision not to receive "aggressive medical treatment" is not the same as withholding all medical care. A patient can still receive antibiotics, nutrition, pain medication, radiation therapy, and other interventions when the goal of treatment becomes comfort rather than cure. This is called palliative care, and its primary focus is helping the patient remain as comfortable as possible. Patients can change their minds and ask to resume more aggressive treatment. If the type of treatment a patient would like to receive changes, however, it is important to be aware that such a decision may raise insurance issues that will need to be explored with the patient's health care plan. Any changes in the type of treatment a patient wants to receive should be reflected in the patient's living will.

Once a living will has been drawn up, patients may want to talk about their decisions with the people who matter most to them, explaining the values underlying their decisions. Most states require that the document be witnessed. Then it is advisable to make copies of the document, place the original in a safe, accessible place, and give copies to the patient's doctor, hospital, and next of kin. Patients may also want to consider keeping a card in their wallet declaring that they have a living will and where it can be found.

Medical Directive

A medical directive is a set of instructions based on likely scenarios of illness, goals for care, and specific treatments, combined with a general values statement. It is also combined with a proxy designation section.

A person who is empowered to make decisions in the place of the patient is sometimes termed a health care proxy or a Durable Power of Attorney for Health Care.

Health Care Proxy and Durable Power of Attorney

A health care proxy is an agent (a person) appointed to make a patient's medical decisions if the patient is unable to do so. Generally, people assign someone they know well and trust to represent their preferences when they can no longer do so. Patients should be sure to ask this person for agreement to act as their agent. An agent may have to exercise judgment in the event of a medical decision for which the patient's wishes are not known.

The durable power of attorney for health care is the legal document that names a patient's health care proxy. Once written, it should be signed, dated, witnessed, notarized, copied, distributed, and incorporated into the patient's medical record. Patients may also want to appoint someone to manage their financial affairs if they cannot. This is called a durable power of attorney for finances, and is a separate legal document from the durable power of attorney for health care. Patients may choose the same person or someone different from their health care proxy to act as their agent in financial matters.

Appropriate forms can be obtained from health care providers, legal offices, Offices on Aging, and state health departments.

Patient Rights

Patients are entitled to complete information about their illness and how it may affect their lives, and they have the right to share or withhold that information from others. Individuals should also be informed about any procedures and treatments that are planned, the benefits and risks, and any alternatives that may be available. Patients may be asked to sign an "informed consent" form, which includes this information. Before signing such a form, patients should read it carefully and ask the doctor any questions they might have.

Patients have the right to make decisions about their own treatment. These decisions may change over time. In the face of worsening disease, some patients may want to try every available drug or treatment in the hope that something will be effective. Other patients may choose to forgo aggressive medical treatment. Many patients turn to family members, friends, or caregivers for advice. But it is the patient's decision how much or how little treatment to have. Sometimes a patient is unable to make this decision, due to severe illness or a change in mental condition.

Common Pitfalls of Advance Care Planning

Anticipating and avoiding the common pitfalls is essential to a successful advance care planning process. These include:

Failing to plan: Do not avoid advance care planning. Too often, situations occur and decisions are made without the benefit of advance care planning. Be proactive. It is easy to forget the central role of the patient, and easy to forget the importance of the proxy. Involve both early and often.

Failing to include the proxy in discussions: Do not leave the proxy decision maker(s) out of the initial discussions with the patient.

Failing to clarify patient preferences: Vague statements can be dangerously misleading. Be sure to clarify patient preferences if they do not seem clear to you or to the proxy. For instance, patients who make statements such as “I never want to be kept alive on a machine” should be asked to clarify whether their wishes would change if their condition were readily reversible, or if their prognosis were unclear.

Focusing discussion too narrowly: Avoid isolated do-not-resuscitate (DNR) discussions; they often create chaotic emotions and thoughts in patients who have to imagine imminent death to make the decision. A DNR discussion is usually an indication that other palliative goals and measures should be considered in the context of a range of scenarios.

Ignoring communicative patients: Sometimes people assume that what a patient indicated for future possible scenarios is what he or she currently wants. As long as the patient is competent, talk to him or her. An impaired patient may still be able to express wishes at some level. In such cases, both the advance directive and tangible evidence of the patient's current wishes should be taken into account.

Failing to read advance directives: Sometimes health care providers assume that they know what is stated in an advance directive. This is a mistake. Advance directives may apply to aggressive intervention, comfort care, or a wide range of specific views and must be read and understood.

Preparation for the Last Stages of Life

Planning for other issues that patients face at the end of their lives is critical if their needs and expectations are to be respected by health care professionals and family members who will survive them. While it would be ideal if all patients and families prepared for death well in advance of the final hours of their lives, most patients with advanced illnesses and their families have neither discussed nor prepared for their death.

As patients approach the last hours of their lives, they have a last chance to finish their business, create final memories, give final gifts, and say their good-

byes. With appropriate assistance, considerable planning can be accomplished around many of these issues.

A refined sense of when the patient and family are ready to engage in this type of planning is needed, as well as a reasonable sense of the patient's prognosis and an ability to distinguish the needs of the patient and family from the feelings of the professionals. Patients and families are often ready for these discussions before the professionals. Such discussions need not be left for the last possible stages. If conducted when patients have a good amount of time left, they can lead to a helpful sense of peace and order while patients get on with living life and seeking their care goals.

In preparing for death, it is important to understand the perspective and wishes of all who are present: the patient, the family, and the caregivers. Personal expectations, agendas, fears, phobias, and acceptable setting(s) for care need to be clear, since any one person may alter the course of care unexpectedly and may interfere with the patient's wishes if they are not clearly known. Personal, cultural, and religious values, beliefs, and practices need to be anticipated and respected, as missed rites or rituals or errors made by unknowing caregivers may have grievous consequences in the eyes of the patient or family members. Identification and acknowledgment that some family members have a need to give care and others don't will enable each to participate as closely as his or her comfort will allow.

Advance Practical Planning

Many patients will choose to get their financial and legal affairs in order, give gifts, and plan for bequests, organ donation, autopsy, burial or cremation, funeral or memorial services, and guardianship of their children as they finish their business. Some patients will even want to give family members permission to build new lives after they die.

Choice of Caregivers

The choice of caregivers for each patient is crucial as vulnerability increases. Early in an illness there is time to discuss and plan for the best configuration. Patients may or may not want family members to care for them. Family members may or may not be able to assume responsibilities for caring and should ideally have the opportunity to be family first and caregivers only if both they and the patient agree to the role. All caregivers need to have the opportunity to change their role if they feel the stress is too great or they are not getting enough chance to finish their personal business with the patient.

Choice of Setting

The choice of the care setting for the last hours of a person's life should be as acceptable as possible to the patient, the family, and all caregivers. Each setting will carry benefits and burdens. Whatever the choice, the setting should permit family members to remain with the patient as much as they wish, and provide

them with opportunities for privacy and intimacy. While dying at home may be the wish of many patients, such a choice may expose family members to undue burden or compromise their careers, their personal economic resources, or their health. If the number of able caregivers and personal resources are limited or if family members are afraid of ghosts and would not be able to live on in their home afterward, care and death in the home may not be the best choice. An alternate inpatient setting may be a hospice or palliative care facility, a skilled nursing facility, or even an acute care facility. Depending on the resources that are locally available and whether the staff is skilled in this kind of care, these alternative settings may lead to a far better outcome.

Decision-Making

Occasionally, choices that are insupportable suggest that the patient is losing decision-making capacity. Reassessment of patient capabilities may be necessary

Decision-making capacity implies the ability to understand and make medical decisions for oneself. It can usually be determined by any physician and does not require a psychiatrist or a court ruling. For a patient to have decision-making capacity, he or she must be able to:

- Understand the information.
- Use it in rational ways to come to a decision.
- Appreciate the consequences of the decision.
- Make a reasonable decision for him/herself.

For example, consider a woman who refuses amputation of a leg for treatment of osteosarcoma. She needs to demonstrate that she understands the information about the condition and the options for care, that she could die if it is not amputated, and that this is a rational decision for her. The patient can meet criteria for decision-making capacity for a particular treatment (i.e., decision-specific capacity), and yet not be competent to handle her practical, financial, and legal affairs. Further, decision-making capacity may vary depending on the treatment decision.

Lack of Capacity

When patients lack the capacity to express their own values and preferences for medical care, goals must be determined by others. For patients who lack decision-making capacity, a proxy decision maker must be determined to help clarify the patient's goals and consent to specific care plans.

Generally, the appropriate proxy is a person selected in advance for this role by the patient, or a person who has knowledge of the patient's values and

preferences and is willing and able to serve in this capacity. When the patient has not preselected a proxy decision maker this usually falls to the next of kin. Legal criteria for proxy selection vary from state to state.

The proxy decision maker should receive guidance to understand his or her role in determining what the patient would want based on available information. Where information is lacking, it becomes necessary to determine what is in the best interest of the patient. This is often, but not always, the same conclusion and often errs toward life prolongation.

To the extent that they are known, the patient's values and preferences should be used to determine the goals of care. Written advance directives, the patient's verbal statements, his or her general values and beliefs, and the way the patient has lived his or her life can all be useful. Together they allow an assessment of what the patient would have judged (i.e., a substituted judgment). Fundamentally, the process demonstrates respect for the patient, and builds trust that the physician and the health care team are acting in the interest of the patient. Further, by focusing on the wishes of the patient, there is reduced guilt or decision regret for the proxy, family members, physician, and health care team.

Here are some practical ways to elicit patient values and preferences in discussions with proxy decision makers:

- “Help me to understand what your husband was like before he got sick. What was most important to him?”
- “Has he ever said anything about how he would want to be treated if he could no longer make decisions for himself?”
- “What would he say in this situation?”
- “Do you have any other family members or friends who have experienced serious illness? Did he or she express how he or she would want to be treated in that situation?”
- “Based on everything you know about him, what do you think he would have wanted in this situation?”

Many of the approaches that work for an advance care planning discussion also work for establishing immediate goals of care, whether working with the patient or a proxy. In particular, it can help to go through a worksheet, using predrafted scenarios, goals, and treatment options, prior to returning to the situation at hand. Clarity and perspective often return with this exercise, which helps in obtaining a broad perspective and allows a comfortable settling into current goals.

Discussing Hospice Care

A referral for hospice care is frequently perceived as challenging. It becomes easier if the idea of hospice care is presented as a response to a need rather than something to turn to when there is nothing left to do.

Elicit the patient's and family's understanding of the current situation before discussing hospice care. If there is an understanding that the main focus should be on comfort, quality of life, and emotional and practical support, hospice care can be introduced as a way for the physician to provide additional resources to care for the patient and family at this time. Patients frequently identify the family as needing the most help. Family members identify the need for a group that will help manage the case and coordinate numerous caregivers and services. Hospice programs are an effective way to provide this.

About 10 to 15% of all patients referred for hospice care are disenrolled (graduate) because they get better with the intensive care and support. There is no penalty for disenrolling and becoming involved later, if needed.

Goals of Care

Hope and Planning

One of the chief obstacles to negotiating goals of care in the face of life-threatening illness and poor prognosis is the issue of hope (i.e., the feeling that what is wanted will happen). Hippocrates stated, and Osler continued to advocate for the medical convention, that “physicians should express hope to the patient and family that the patient will enjoy a full recovery from the current illness, even if it is not true.” Its most recent interpretation is that positive mental imagery is required for disease to be cured. This principle has been mistakenly taken so far as to administer treatments that are known to be ineffective, even to cause harm, in the service of maintaining hope.

Planning that gives a sense of future and working toward a goal reinforce hope. When patients learn they have a life-threatening disease, many first hope it is not true. Later, their hope shifts and they hope they will not die from it. Next, they think a bit about what they will do if either turns out to be likely. The point is, most adults cope and sustain hope by making plans for the future, even if the future is not what they would want if they could choose.

Most adults have the capacity to hope and plan for several possibilities simultaneously. They can “hope for the best, but prepare for the worst.” Most of us can recall a variety of situations in which this is true. How many of us have had a cherished hope as well as a plan if it didn't happen? Getting the best score on the exam? Being named valedictorian? Starting for the football team?

Hope is quite resilient, even in the face of hard realities. It is different from wishing. Hope can be defined as the expectation that something good or anticipated will happen in the future. There is a spectrum of goals both patients and providers can hope for. They can hope the illness will be cured, or that it will not come back for a long time, or that its progression will be stopped, or that symptoms will be controlled, or that important business can be accomplished before a good death, or that death will be comfortable and safe, or that family will recover from their bereavement.

Goals

Since the beginning of medicine, there have been two overall aims of care: to cure disease and to relieve suffering. Both strive to maintain the patient's capacity to live life to the fullest and realize her or his full potential. Within these two overall aims are numerous possible goals for health care, including complete cure, avoidance of premature death, maintenance or improvement in function, prolongation of life, relief of various types of suffering, improvement of quality of life, preservation of control, a good death, and support for families and loved ones. No one goal is inherently more valid than another; all are legitimate goals of medicine and each will be applied differently by the individual in his or her particular circumstance.

As patients and families experience life-threatening illness, several concepts become apparent to the observant clinician.

Although goals may seem to stretch along a continuum in a linear fashion, in fact the patient and health care provider may want to both control/cure the disease and manage the symptoms and other issues that cause them suffering (i.e., treat the cause and manage the experience). They may not consider a therapeutic intervention (e.g., chemotherapy) unless it addresses both goals. In clinical practice this is more the rule than the exception.

Over the course of a lifetime, or the course of an illness, the relative weight given to each goal and each treatment may change in response to numerous factors. It is only in the context of an individual's life that an adequate balance of goals can be achieved.

As a patient's prognosis and health status worsen, the goals of prevention, cure, and avoidance of death may become less important as they become less possible. At the same time, the goals of maintaining function, relieving suffering, and optimizing quality of life may become the focus of care.

Ideally, this shift in focus of care is gradual. It is usually negotiated over time. An abrupt transition in the focus of care from primarily curative care to primarily supportive care is rarely appropriate. The shift in goals is an expected part of the continuum of care. Clinical decisions routinely require prioritization among

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potentially contradictory goals. Such tradeoffs are an inevitable part of medical care. Changes occur throughout the patient's life and illness.

Primary Emphases of Care for Those with Different Goals Related to Life-Threatening Illness or Injury			
	Primary Goal of Care		
Aspect of Care	Curative	Palliative/Life-Prolonging	Palliative/Symptomatic
Impact on disease	Eradicate	Arrest progression	Avoid complications
Acceptable adverse effects	Major	Major-moderate	Minor-none
Psychological attitude	"Win"	"Fight"	"Accept"
Preference for CPR	Yes	Probably	Probably Not
Hospice candidate	No	No	Probably
Symptom prevention/relief	Secondary	Balanced	Primary
Support for family	Yes	Yes	Yes
Advance care planning	Yes	Yes	Yes
Bereavement support	Not usually	Sometimes	Usually
Adapted from Institute of Medicine. Approaching Death: Improving Care at the End-of-Life. Washington, DC: National Academy Press; 1997:83.			

Transitional Care

Overview

Nearly 90% of all care for life threatening illness is delivered in outpatient settings. This places increased responsibility on the patient and family and requires a coordinated approach by the health care system. While health care

continues to increase in complexity, regulatory and fiscal pressures have become more restrictive.

Optimal care is now dependent on careful planning across different care settings to ensure a continuum of care. Patients now move across numerous care settings during treatment (e.g., the transition from being an inpatient at a hospital to being an outpatient in need of home care). Key components to successful outpatient and home care treatment of patients with terminal illnesses are a coordinated team for delivery of health care, an involved and committed patient and/or family, and the availability of ongoing support and education for the patient and family.

Not only is the delivery of care at risk if care is fragmented, but the demands of illness may place families at risk for job loss and economic hardship as they struggle to care for their family members at home. The planning for and delivery of home care services to patients and their families are often fragmented. The most vulnerable - such as those with a low income, urban-dwelling minorities, and those in a rural setting - may be at a higher risk of experiencing fragmented care.

A team approach to the care of patients and their families is optimal to meet their needs, which frequently are unrecognized and complex. Depending on the diagnosis, disease stage, level of nursing care required, and a variety of psychosocial factors, patient needs range from low technology to high technology and from low intensity of support to high intensity of support. Care needs are dictated by medical and biologic factors and by demographics, setting (urban vs. rural), and psychosocial factors. Thus, care needs are unique to each patient and family. However, the delivery of care for those in transition and for those in need of assessment, planning, and ongoing management is challenging and time consuming and may become unsystematic and haphazard.

Definitions

Transitional care can be defined as care that is required to facilitate a shift from one disease stage and/or place of care to another. For example, as a disease progresses, a patient may proceed through phases of illness that require vastly different levels of emphasis in the goals of care and, consequently, in the nature of care delivery. An individual may have a disease that is amenable to curative therapy; the major goal of therapy may focus on this. Alternatively, another stage of illness may be more amenable to an intense focus on palliation. In many cases, a balance between curative therapy and palliation is the goal.

For increasing numbers of individuals, challenging transitions also occur from illness to health. Transitions also occur with movement from one level of care to another, such as from inpatient acute care to subacute care, nursing home, rehabilitation facility, home care, or hospice care. The process of planning for

these transitions is frequently referred to as discharge planning because it implies a release from one facility to another. Transitions may occur on an outpatient basis when the patient no longer benefits from curative therapy and would benefit from a hospice or palliative care referral made directly by the outpatient staff. Nonetheless, discharge planning must embrace the concept of the continuum of care, or care will become fragmented.

The site of care is dictated by disease stage and/or associated comorbid factors that complicate treatment, by patient or family values and goals of care, and by fiscal or other factors associated with access to care. All transitions necessitate some degree of change. A change, whether viewed as positive or negative, generates stress for the patient, family, and staff. Protocols for these transitions should be developed with the goal of minimizing stress and ensuring good patient care.

Optimal and successful transitions can be ensured through an integrated, seamless relationship between inpatient and outpatient care. Outpatient care is broadly defined to include home care, rehabilitation units or centers, skilled nursing facilities, nursing homes, and hospice care. Discharge planning can be improved through a coordinated systems approach, which may place a community liaison nurse and/or social worker as intermediaries among the hospital, major home health care companies, rehabilitation facilities, nursing homes, and other supportive care resources.

A coordinator of the diverse array of health care professionals is imperative, and communication between the professionals is most important. Often, it is the person with the illness or his or her family who carries information from one member of the health care team to another. As an illness becomes more burdensome and complex, a formalized and defined mechanism that is clear to all team members is imperative. Underpinning the approach to patient care should be a biopsychosocial model that assumes that illness is not only a biological phenomenon but also a psychological and social one. In addition, and most importantly, this model must underpin transitions through varying goals of care and foci of treatment.

Routine and comprehensive biopsychosocial evaluation performed by a trained member of the health care team, preferably a medical social worker or a clinical nurse specialist, should complement the physician's efforts to begin the planning of a strategy of care. For the assessment of the overall goals of care, it is imperative that the treating clinician be cognizant of the need to guide the patient through the varying options for care based on the balance between disease status, treatment possibilities, functional status, patient and family goals, and their interpretation of quality-of-life parameters. Ideally, the assessment of transitional needs should be performed at the time of admission to any inpatient facility and at critical points during the course of disease, including diagnosis, completion of curative treatment protocols, relapse, and terminal phase. It is

essential that this assessment be routine because many changes will occur over time in the patient's and family's goals of care, and in the family's willingness and ability to care for the patient. Reassessment is essential for successful home care, medical compliance, and stress management. Routine re-evaluations of the patient and family biopsychosocial status need to be part of the management process in both inpatient and ambulatory care.

Special Considerations

Home Care Considerations

Caring for a patient at home places increased technical and emotional demands on the family. Many families have numerous out-of-home responsibilities and, in addition, family members might be physically or psychosocially compromised and thus unable to assume the primary care role. The following factors need to be assessed when determining whether a spouse or caregiver can handle home care: the caregiver's age, health, motivation, and sex (women are more likely to provide home care); the length of hospital stay (prolonged stay may complicate transition to home care); other demands on the caregiver; the degree of patient distress (particularly pain); the technical nature of care; and decision-making skills required for care delivery.

Some patient groups are at a higher risk (e.g., older women who are alone and poor and who have multiple chronic illnesses are at higher risk for difficulties after they leave the hospital). Rural patients are also at higher risk for home care complications, particularly if the terminal phase of disease is prolonged and physical debilitation increases. Access to available health care may be limited. The importance of assessing the family's motivation and ability to provide care for the patient cannot be stressed enough. Assessment must be broad and include the areas discussed above, and where appropriate, must also include the level of pre-existing interpersonal conflicts and the family's beliefs and values with regard to home care, dying, and the use of opioids for pain control. Adequate pain and symptom management is a key component to successful home management, but this can only be accomplished if the family and primary caregiver understand the need for the control of pain and other symptoms.

Health care providers and caregivers need to understand that uncontrolled symptoms, particularly poorly controlled pain, can dramatically increase the physical and psychological burdens of caregiving. There should be an understanding of whom to call for support or advice regarding problems that may arise. As an illness progresses, the need for consistent personnel who know the ill person's situation becomes the key component of successful delivery of care in the home.

The central role of family caregivers in patient management is increasingly recognized. Family caregivers play an essential role in promoting compliance with medical treatment, managing side effects, performing practical tasks, and providing emotional and social support. It is also noteworthy that caregivers often function as proxies for patients in reporting symptoms and psychological distress; however, family caregivers tend to overestimate the psychosocial distress of patients, which may be a result of their own underreported burden and distress.

Insurance and Financial Considerations

Other important issues for assessment in transitional care planning include insurance coverage, the availability of community resources, and legal concerns. Most insurance companies cover home care, but some policies limit services to specified settings; for example, payment may depend on the patient having already been hospitalized or needing skilled nursing services. It is important to ascertain insurance limits on specific services as well as lifetime limitations. Primary care physicians, nurses, and social workers may need to assume the role of patient advocate when dealing with third-party insurers, case managers, and managed care companies. For these reasons it is important to design a home care plan that provides adequate safety to the patient, is least distressing to the family, and utilizes resources appropriately. It is often helpful to explore other resources that do not require insurance or patient payment, including sectarian as well as nonsectarian family agencies, which may provide limited unskilled services. Nursing assistants and aides (unskilled nursing services) are usually not covered by insurance; however, hospice care may cover this expense. Proprietary home care services provide this care but at the expense of the patient and family.

Caregiving

When caring for a patient at home, there may be times when the caregiver needs assistance from the patient's health care team. A caregiver should contact the patient's doctor or nurse for help in any of the following situations:

- The patient is in pain that is not relieved by the prescribed dose of pain medication;
- The patient shows discomfort, such as grimacing or moaning;
- The patient is having trouble breathing and seems upset;
- The patient is unable to urinate or empty the bowels;
- The patient has fallen;
- The patient is very depressed or talking about committing suicide;
- The caregiver has difficulty giving medication to the patient;

- The caregiver is overwhelmed by caring for the patient, or is too grieved or afraid to be with the patient; or
- At any time the caregiver does not know how to handle a situation.

Everyone has different needs, but some emotions are common to most dying patients. These include fear of abandonment and fear of being a burden. They also have concerns about loss of dignity and loss of control. Some ways caregivers can provide comfort are as follows:

- Keep the person company—talk, watch movies, read, or just be with the person.
- Allow the person to express fears and concerns about dying, such as leaving family and friends behind. Be prepared to listen.
- Be willing to reminisce about the person's life.
- Avoid withholding difficult information. Most patients prefer to be included in discussions about issues that concern them.
- Reassure the patient that you will honor advance directives, such as living wills.
- Ask if there is anything you can do.
- Respect the person's need for privacy.

Loss, Grief, Bereavement, Mourning

All terminally ill patients and their families experience losses. Loss, grief, and bereavement are a significant part of the end of life experience.

The progression from the final stages of life to the death of a loved one is experienced in different ways by different individuals. Coping with death is usually not an easy process and cannot be dealt with in a cookbook fashion. The overall experience is defined by countless contributing factors, including all of the following: the manner of death, one's cultural and religious beliefs, coping skills, and psychiatric history; the availability of support systems; and one's socioeconomic status.

Distinguishing between the following terms is important: loss, bereavement, grief, and mourning. These terms are sometimes used interchangeably, yet often with different intentions.

Loss

The impact of illness on patients varies widely, dependent on prognosis. Each family member will experience her/his own secondary losses as well as having

reactions to the patient's losses. The family system will have to cope with and adapt to the changes. Sometimes these adaptations will be constructive; sometimes not.

Individuals with terminal illness and their families experience many different losses throughout their experience. For the family, the experience of loss continues during and after the death of the patient. Loss of a sense of future, ability to function, former body image, relationships, control, independence, dignity, etc., can occur at any time. As patients' illness progresses, the risk of losing control over fundamentally important aspects of their lives increases, often dramatically.

The time course of patients' and families' adaptation to loss varies. Assimilating the reality of a loss can take days to weeks. Adjusting to the loss can take weeks to months or even years.

Patient Losses

Sense of Future - The first loss a patient with a progressive illness faces often is loss of confidence about the future. Even patients who do not lose hope probably confront this adjustment in some fashion. A terminal disease diagnosis almost inevitably raises a person's awareness of mortality and places it in a new light. This existential challenge is likely to have ramifications in the psychological and relational domain.

Function - Whether it is the disease or the treatment that impacts function, patients must accommodate a wide range of transient and permanent losses of function (i.e., onset of fatigue; inability to perform activities of daily living; or loss of normal taste, hearing acuity, or fine cognitive skills). Adaptations often involve family members in new activities such as shopping for the first time or helping the patient with toileting or other activities of daily living. The family member may have to develop new skills to perform these new activities.

Material - As personal challenges mount and personal resources are expended in response, material losses also accumulate. Financial losses occur due to lost income, medical bills, and practical life changes such as relocating or paying for caregiving. These material losses also induce emotional reactions and drain a person's coping resources.

Family Losses

Patient losses result in family losses. As the patient loses function, the family tends to take up the slack. This may entail gains in roles or relationships, but there are usually losses as well. Family members may have to give up work; modify their expectations of a mother, spouse, or child; make time to perform domestic functions; and so on. Adaptations by family members are an integral part of the process of living with terminal illness, adjusting to losses, and coping with eventual bereavement. Comprehensive care requires awareness of

adjustments by family members and interventions to aid the process. The patient is not likely to do as well if his or her family is failing to cope.

The Health Care Team and Loss

The cumulative effect of loss on the health care team can be overwhelming. To enhance their own effectiveness, those in the helping professions need to be keenly aware of their own vulnerability and take the necessary steps to protect themselves. Feelings of powerlessness, inadequacy, and isolation can be mitigated by self-care approaches that incorporate mental, physical, emotional, and spiritual dimensions. Balancing work life with other activities will assist the health care team in responding to the emotional needs of patients and their families.

Bereavement

Bereavement is the period after a loss during which grief is experienced and mourning occurs. The length of time spent in a period of bereavement depends on the intensity of the attachment to the deceased and how much time was involved in anticipation of the loss.

Phases of Bereavement

The conceptual framework of the attachment theory (the bonds that are formed early in life with parental figures derive from the need to feel safe and secure) and of human information processing (the process used to filter out or let through unwanted information) have been combined to explain loss and bereavement. The bereavement process can be divided into four phases:

1. **Shock and Numbness:** During this initial phase, survivors have difficulty processing the information of the loss; they are stunned and numb.
2. **Yearning and Searching:** In this phase, there is a combination of intense separation anxiety and disregard or denial of the reality of the loss. This engenders a desire to search for and recover the lost person. Failure of this search leads to repeated frustration and disappointment.
3. **Disorganization and Despair:** In this phase, individuals often report being depressed and have difficulty planning future activities. These individuals are easily distracted and have difficulty concentrating and focusing.
4. **Reorganization:** This phase overlaps somewhat with the third phase.

The phases modulate to allow existing internalized, representational figures of safety and security to be reshaped, incorporating the changes that have occurred in the life of the bereaved.

Grief

Immediately after a death, those who are bereaved will need time to recover from their acute stress and fatigue and restore their environments to normal. As they begin to live with the significance of their loss, they will likely experience an intense grief reaction with multiple cognitive, emotional, and physical responses and require considerable ongoing support to help them deal with all the changes to their lives. Some people who are bereaved will make a conscious effort to deal with the loss, emotions, and changes that follow the death of a loved one. They may seek ongoing assistance to help address their feelings of loss. Others will deny what is happening and avoid dealing with any of these issues. They will be at high risk for a prolonged, complicated grieving process.

Families with a member who has terminal illness are in a nonlinear transition from living with illness to experiencing a death.

Theoretical perspectives have offered frameworks for understanding why we grieve. Bowlby suggests that grief occurs when an attachment necessary to one's safety and security is disrupted. Others conceive grief as a part of the healing process, reestablishing equilibrium in a person's life after the loss of a loved one.

Most theories conceptualize grief after a death as encompassing multiple sensations and experiences, including:

- Emotional (e.g., sadness, anxiety, anger)
- Physical (e.g., loss of appetite, fatigue)
- Cognitive (e.g., preoccupation, confusion)
- Behavioral (e.g., restlessness, searching)
- Spiritual (e.g., questioning beliefs, anger at God)

Uncomplicated grief

Uncomplicated grief reactions include a wide range of physical, emotional, spiritual, and cognitive behaviors. The bereaved may note feelings of hollowness in the stomach, tightness in the chest, heart palpitations, weakness, lack of energy, gastrointestinal disturbances, weight gain or loss, or skin reactions. Many say they feel emotional numbness, relief, sadness, fear, anger, guilt, loneliness, abandonment, despair, or ambivalence. The bereaved may be concerned about cognitive symptoms such as disbelief, confusion, inability to concentrate, and preoccupation with or dreams of the deceased. All of these are expected grief reactions to a loss.

Worden suggests four tasks of grief:

1. Accepting the reality of the loss

2. Experiencing the pain of grief
3. Adjusting to an environment in which the deceased is missing
4. Withdrawing emotional energy from the deceased and reinvesting in other relationships

These tasks should be seen as guides for what the bereaved may experience. The bereaved do not go through these in a scripted manner, but in a variety of ways and with different timing for each person.

Worden and others have defined benchmarks from which to judge the resolution of the grief process, when:

- The bereaved is able to talk about the deceased without intense, fresh feelings of loss.
- The survivor is able to invest energy in new relationships, roles, and responsibilities, without disabling guilt and feelings of disloyalty toward the deceased.

Complicated grief

Some people who are bereaved continue to experience intense cognitive, emotional, and physical grief reactions over long periods of time that interfere with their physical or emotional well-being. When this occurs, it suggests that the person is experiencing complicated grieving that needs more attention.

Complicated or pathological grief reactions are maladaptive extensions of normal bereavement. These maladaptive reactions overlap psychiatric disorders and require more complex, multimodal therapies than do uncomplicated grief reactions. Adjustment disorders (especially depressed and anxious mood or disturbance of emotions and conduct), major depression, substance abuse, and even posttraumatic stress disorder (PTSD) are some of the more common psychiatric sequelae of complicated bereavement. Grief that becomes pathologic is often identifiable by lingering symptomatology, increased disruption of psychosocial functioning caused by the symptoms, or the intensity of subsyndromal symptoms (e.g., intense suicidal thoughts or acts upon the loss).

Complicated or unresolved grief can take many forms. Complications may manifest as absent grief (i.e., grief and mourning processes are totally absent), inhibited grief (a lasting inhibition of many of the manifestations of normal grief), delayed grief, conflicted grief, or chronic grief. Risk factors for pathologic grief include suddenness of loss; gender of the bereaved; and the existence of an intense, overly close, or highly ambivalent relationship to the deceased. Pathologic grief reactions that extend to major depressive episodes should be treated with combined drug and psychotherapeutic interventions, though the efficacy of these combined approaches is untested. The bereaved who maintain

long-standing avoidance of any and all reminders of the deceased, who re-experience the loss or the presence of the deceased in illusions or intrusive thoughts or dreams, and who startle and panic easily at reminders of the loss might be considered for a diagnosis of PTSD (even without meeting all the criteria for a psychiatric diagnosis). Substance abuse in the bereaved is frequently an attempt at self-medication of painful feelings and symptoms (such as insomnia) and can be targeted for drug and psychotherapeutic intervention.

There are four categories of complicated grief reactions:

- **Chronic grief** is characterized by normal grief reactions that do not subside and continue over very long periods of time.
- **Delayed grief** is characterized by normal grief reactions that are suppressed or postponed. The person consciously or unconsciously avoids the pain of the loss.
- **Exaggerated grief** is characterized by coping strategies that accelerate and even become destructive, especially in the face of a seemingly insurmountable loss (i.e., increased smoking/alcohol/medication intake, overworking, even suicidal ideation).
- **Masked grief** is characterized by oblivion that the behaviors that interfere with normal functioning are a result of the loss.

Both uncomplicated and complicated grief can continue for several months to several years. Grief may continue longer in some situations. Mediating factors include:

- Mode of death (e.g., natural, traumatic)
- Preexisting emotional states (e.g., depression, stress)
- Personality variables (e.g., coping, resilience)
- Social and cultural context (e.g., traditions, rituals, social network)
- Relationship(s) to the deceased (e.g., close, conflicted, or ambivalent; loss of a child or loss of a long-term marital partner)

It is the duration as well as the intensity of the symptoms, coupled with a diminished ability to function, that help to distinguish uncomplicated from complicated grief. Worden provides clues to diagnosing complicated grief:

- Inability to speak about the loss without experiencing intense and fresh grief
- Relatively minor events trigger intense grief reactions

- Themes of loss permeate clinician's interview
- Unwilling to move material possessions
- Physical symptoms similar to those of the deceased
- Radical changes of lifestyle
- History of subclinical depression, often with persistent guilt and lowered self-esteem, or the opposite, false euphoria
- Compulsion to imitate the deceased
- Self-destructive impulses
- Unaccountable sadness occurring at a certain time each year (although anniversary reactions, or increased intensity of grief during holidays, birthdays, etc., are a normal part of the uncomplicated grief process).
- Phobia about illness or about death

Bonanno and others have found that psychological resilience is more common during bereavement than previously thought. These works suggest that there are multiple trajectories for the grief process, including those involving intense, negative emotional experiences throughout the course as well as those involving psychological growth.

Exaggerated grief responses include major psychiatric disorders that develop following a loss and include recognized diagnoses in the American Psychiatric Association's Diagnostic and Statistical Manual (DSM). Clinical depression is one example.

Anticipatory Grief

Anticipatory grief refers to a grief reaction that occurs in anticipation of an impending loss. Anticipatory grief is the subject of considerable concern and controversy.

The term anticipatory grief is most often used when discussing the families of dying persons, although dying individuals themselves can experience anticipatory grief. Anticipatory grief includes many of the same symptoms of grief after a loss. Anticipatory grief has been defined as “the total set of cognitive, affective, cultural, and social reactions to expected death felt by the patient and family.”

The following aspects of anticipatory grief have been identified among survivors:

- Depression.
- Heightened concern for the dying person.

- Rehearsal of the death.
- Attempts to adjust to the consequences of the death.

Anticipatory grief provides family members with time to gradually absorb the reality of the loss. Individuals are able to complete unfinished business with the dying person (e.g., saying “good-bye,” “I love you,” or “I forgive you”).

Anticipatory grief cannot be assumed to be present merely because a warning of a life-threatening illness has been given or because a sufficient length of time has elapsed from the onset of illness until actual death. A major misconception is that anticipatory grief is merely conventional (post-death) grief begun earlier. Another fallacy is that there is a fixed volume of grief to be experienced, implying that the amount of grief experienced in anticipation of the loss will decrease the remaining grief that will need to be experienced after the death.

Several studies by Glick and Parkes have provided clinical data documenting that grief following an unanticipated death differs from anticipatory grief. Unanticipated loss overwhelms the adaptive capacities of the individual, seriously compromising his or her functioning to the point that uncomplicated recovery cannot be expected. Because the adaptive capacities are severely assaulted in unanticipated grief, mourners are often unable to grasp the full implications of their loss. Despite intellectual recognition of the death, there is difficulty in the psychological and emotional acceptance of the loss, which may continue to seem inexplicable. The world seems to be without order, and like the loss, does not make sense.

Some researchers report that anticipatory grief rarely occurs. They support this observation by noting that the periods of acceptance and recovery usually observed early in the grieving process are rarely found before the patient’s actual death, no matter how early the forewarning. In addition, they note that grief implies that there has been a loss; to accept a loved one’s death while he or she is still alive can leave the bereaved vulnerable to self-accusation for having partially abandoned the dying patient. Finally, anticipation of loss frequently intensifies attachment to the person.

Although anticipatory grief may be therapeutic for families and other caregivers, there is concern that the dying person may experience too much grief, thus creating social withdrawal and detachment. Research indicates that widows usually remain involved with their dying husbands until the time of death. This suggests that it was dysfunctional for the widows to have begun grieving in advance of their husbands’ deaths. The widows could begin to mourn only after the actual death took place.

Assessing Grief

Indicators of uncomplicated grief include incorporating the loss into one's life and beginning to enter into meaningful relationships and activities again. Even in uncomplicated grief, this movement forward is painful.

Effectively anticipating and reducing the severity of the grief reactions of patients and families begins early in the process and involves repeated assessment of anticipated and actual losses, emotional responses, and coping strategies. Cognitive, emotional, and physical reactions to grief, and the need for bereavement support, can be ongoing for months.

Recognition that grief may be the underlying cause of a patient's physical complaints is important if useless or misleading investigations or medication trials are to be avoided. To effectively anticipate and reduce the intensity of grief reactions, assess each patient's anticipated and actual losses, emotional responses, and coping strategies frequently during the first months following a death. Gentle inquiry can help the healthcare professional understand how the survivor is coping and provide support.

When religion is an important component of coping, engage a chaplain or pastoral care professional to help determine and understand the religious background and framework held by each family member.

Try to identify individuals who are at particular risk early. Physicians and other health care workers need to be skilled at assessing grief reactions, providing basic supportive care, and referring individuals to bereavement experts expeditiously when grief reactions become complicated.

Some people will make a conscious effort to manage the loss. Others will deny what is happening and avoid dealing with the loss. Some coping strategies (e.g., increased smoking/alcohol/medication intake, overworking, and suicidal ideation) may accelerate and even become destructive, especially in the face of seemingly insurmountable loss.

Health care providers need to be attuned to behaviors that might indicate complicated grief, especially if these continue beyond 6 to 12 months. The survivor may not be able to speak of the deceased without experiencing intense sadness. Themes of loss may continue to occur in every topic during a clinical interview. Minor events may unexpectedly trigger intense grief and sadness. The survivor may be unwilling to move possessions belonging to the deceased. Sometimes the survivor will develop symptoms similar to those of the deceased.

Ongoing assessment will help the clinician distinguish uncomplicated from complicated grief reactions. Understanding the bereaved person's preexisting conditions is beneficial as those conditions may complicate the grief process. Preexisting clinical depression, for instance, can predispose someone to a

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complicated grief process. Many symptoms of normal grief are similar to those of mental health disorders. Differentiating normal grief from mental health disorders is helped by factoring in the intensity, duration, and impact on functioning for the bereaved. Clinical depression is a good example because both grief and depression are associated with intense low mood, difficulty experiencing pleasure, sleep disturbance, and appetite loss, making it difficult to distinguish among them.

Uncomplicated Grief vs Clinical Depression (adapted from Cook & Dworkin, 1992)		
	Uncomplicated Grief	Clinical Depression
Loss	Recognizable and current	May be associated with a loss; loss is not always recognizable, and may be symbolic
Reactions	Initially intense, then variable	Intense and persistent
Mood	Labile, acute, heightened when thinking about loss	Consistent low, pervasive, chronic, absence of emotion
Behavior	Variable, shifts from being able to share pain to wanting to be alone, variable refusals of enjoyable activities	Refusals of most previously enjoyed activities, no enthusiasm, consistent difficulty enjoying activity
Anger	Often expressed	Self-directed
Sadness	Periodic weeping or crying	Little variability (inhibited or uncontrolled expression)
Cognition	Preoccupied with loss, confusion	Preoccupied with self, worthlessness, self-blame, hopelessness
History	Little history of psychiatric disorder	Previous history of depression or other psychiatric disorder
Sleep	Periodic difficulties falling asleep and with early morning awakening	Regular early morning awakening
Imagery	Vivid dreams, capacity for imagery and fantasy	Self-punitive imagery
Responsiveness	Responds to warmth and assurance	Limited responsiveness to others

Mourning

Mourning is the act of grieving --the outward expression of a loss. Grief and bereavement are part of the process of adjusting to a loss. Mourning can involve private expressions of grief as well as socially or culturally defined customs such as rituals and traditions.

The three phases of mourning are :

1. The urge to recover the lost person.
2. Disorganization and despair.
3. Reorganization.

These phases grew out of the attachment theory of human behavior, which postulates that people need to attach to others to improve survival and reduce risk of harm.

Managing Loss

Most of the support that people receive after a loss comes from friends and family, but physicians and other health care professionals can identify and orchestrate mechanisms for support and healing and make an important difference. For those who are experiencing particularly difficult problems in their bereavement, specific interventions may be considered. Psychotherapeutic interventions for grief vary widely and include individual and group methods. Treatment methods found to be effective with various populations of bereaved individuals include time-limited dynamic psychotherapy, cognitive-behavioral intervention, hypnotherapy, and trauma desensitization.

Grief counseling and grief therapy are distinguished from each other. Grief counseling guides uncomplicated (normal) grief to a healthy completion of the tasks of grieving within a reasonable time frame, usually without a time-limited template. Grief counseling can be provided by professionally trained individuals or in self-help groups in which bereaved persons offer help to other bereaved persons. All of these services can be offered in individual or group settings. Grief counseling seems to be most useful for bereaved persons who perceive their families as unsupportive or who, for other reasons, are thought to be at special risk.

The goals of grief counseling include the following:

- Helping the bereaved to actualize and to accept the loss, most often by helping him or her to talk about the loss and the circumstances surrounding it.
- Helping the bereaved to identify and express feelings related to the loss (e.g., anger, guilt, anxiety, helplessness, or sadness).

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- Helping the bereaved to live without the deceased and to make independent decisions.
- Helping the bereaved to withdraw emotionally from the deceased and to begin new relationships.
- Providing support and time to focus on grieving at critical times such as birthdays and anniversaries.
- Normalizing appropriate grieving and explaining the range of individual differences in this process.
- Providing ongoing support, usually not on a time-limited basis (as with grief therapy).
- Helping the bereaved to understand his or her coping behavior and style.
- Identifying problematic coping mechanisms and making referrals for professional grief therapy.

Bereavement is among the most disruptive of all life processes, and it is difficult to put an arbitrary limit on its expected duration. Grief therapy is used with people who have abnormal or complicated grief reactions. The goal of grief therapy is to identify and resolve the conflicts of separation that interfere with the completion of the tasks of mourning. The conflicts of separation may be absent or masked as somatic or behavioral symptoms; delayed, inhibited, excessive, or distorted mourning; conflicted or prolonged grief; or unanticipated mourning (though this is usually not present with cancer deaths).

Grief therapy can be provided on an individual basis or in group therapy. Regardless of setting, a therapeutic contract is established with the patient to define the time-limited basis of the therapy, any fees, and the expectations and focus of the therapy. If the patient presents with physical complaints, medical illness must be ruled out.

Grief therapy requires talking about the deceased and recognizing whether there are minimal or exaggerated emotions surrounding the loss. Persistently idealized descriptions of the deceased can be indicators of the presence of more ambivalent, angry feelings. Grief therapy may allow the individual to see that anger, guilt, or other negative or uncomfortable feelings do not preclude more positive ones, and vice versa.

The focus of grief therapy depends on an assessment of the four tasks of mourning. Human beings tend to make strong affectional bonds or attachments with others. When these bonds are severed, as they are in death, a strong emotional reaction occurs. The tasks of mourning serve as a means whereby grief may be resolved. After one sustains a loss, certain tasks of mourning must be accomplished for equilibrium to be established and for the process of mourning to be completed.

Adaptation to loss may be seen as involving the following four basic tasks:

1. Acceptance of the reality of the loss.

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2. Working through and experiencing the physical and emotional pain of grief.
3. Adjusting to an environment in which the deceased is missing.
4. Emotionally relocating the deceased and moving on with life.

It is essential that the grieving person complete these tasks before mourning can be accomplished.

Six tasks of grief have been identified to help focus problem-specific therapeutic interventions for bereaved spouses:

1. Develop the capacity to experience, express, and integrate painful grief-related affects.
2. Use the most adaptive means of modulating painful affects.
3. Establish a continuing relationship with the deceased spouse.
4. Maintain one's own health and continued functioning.
5. Achieve a successful reconfiguration of altered relationships and understand why others may have difficulty empathizing with the bereaved.
6. Achieve an integrated, healthy self-concept and stable worldview.

Complications in grief may arise because of unresolved grief related to earlier losses. The grief from these previous losses must be managed so that the current grief can be resolved. Additionally, identification of transitional or linking objects that allow the relationship with the deceased to be maintained externally is useful because the objects may be interrupting successful completion of the grieving tasks. One author (Rando; 1993) notes that grief therapy includes dealing with resistances to the mourning process, identifying unfinished business with the deceased, and identifying and accommodating secondary losses resulting from the death. Ultimately, the bereaved is helped to accept the finality of the loss and to picture what his or her life will be like after the bereavement period. It is helpful to acknowledge that repetition may be a part of treatment, but only when in the service of working through the grief.

Children and Loss

At one time children were considered miniature adults, and their behaviors were expected to be modeled as such. Today there is a greater awareness of developmental differences between childhood and other developmental stages in the human life cycle. Differences between the grieving process of children and that of adults are recognized. It is now believed that the real issue for grieving children is not whether they grieve, but how they exhibit their grief and mourning. The primary difference between bereaved adults and bereaved children is that intense emotional and behavioral expressions are not continuous in children. A child's grief may appear more intermittent and briefer than that of an adult but in fact usually lasts longer. The work of mourning in childhood needs to be addressed repeatedly at different developmental and chronological milestones.

Because bereavement is a process that continues over time, children will revisit the loss repeatedly, especially during significant life events (e.g., going to camp, graduation from school, marriage, and the birth of their own children). Children must complete the grieving process, eventually achieving resolution of grief.

Although loss is unique and highly individualized, several factors can influence a child's grief. These factors include the child's age, personality, stage of development, previous experiences with death, previous relationship with the deceased, the environment, the cause of death, patterns of interaction and communication within the family, stability of family life after the loss, how the child's needs for sustained care are met, availability of opportunities to share and express feelings and memories, parental styles of coping with stress, and the availability of consistent relationships with other adults.

Children do not react to loss in the same ways as adults and may not display their feelings as openly as adults do. In addition to verbal communication, grieving children may employ play, drama, art, school work, and stories. Bereaved children may not withdraw into preoccupation with thoughts of the deceased person; they often immerse themselves in activities (e.g., they may be sad one minute and then playing outside with friends the next). Families often incorrectly interpret this behavior to mean the child does not really understand or has already gotten over the death. Neither assumption may be true; children's minds protect them from thoughts and feelings that are too powerful for them to handle. Grief reactions are intermittent because children cannot explore all their thoughts and feelings as rationally as adults can. Additionally, children often have difficulty articulating their feelings about grief. A grieving child's behavior may speak louder than any words he or she could speak. Strong feelings of anger and fear of abandonment or death may be evident in the behaviors of grieving children. Children often play death games as a way of working out their feelings and anxieties in a relatively safe setting. These games are familiar to the children and provide safe opportunities to express their feelings.

Grief and Developmental Stages

Death and the events surrounding it are understood differently depending on the age and developmental stage of the child.

Infants

Although infants do not recognize death, feelings of loss and separation are part of a developing death awareness. Children who have been separated from their mothers and deprived of nurturing can exhibit changes such as listlessness, quietness, unresponsiveness to a smile or a coo, physical changes (including weight loss), and a decrease in activity and lack of sleep.

Ages 2 to 3 years

In this age range, children often confuse death with sleep and can experience anxiety. In the early phases of grief, bereaved children can exhibit loss of speech and generalized distress.

Ages 3 to 6 years

In this age range, children view death as a kind of sleep: the person is alive, but in some limited way. They do not fully separate death from life and may believe that the deceased continues to live (for instance, in the ground where he or she was buried) and often ask questions about the activities of the deceased person (e.g., how is the deceased eating, going to the toilet, breathing, or playing?). Young children can acknowledge physical death but consider it a temporary or gradual event, reversible and not final (like leaving and returning, or a game of peek-a-boo). A child's concept of death may involve magical thinking, i.e., the idea that his or her thoughts can cause actions. Children may feel that they must have done or thought something bad to become ill or that a loved one's death occurred because of some personal thought or wish. In response to death, children younger than 5 years will often exhibit disturbances in eating, sleeping, and bladder or bowel control.

Ages 6 to 9 years

It is not unusual for children in this age range to become very curious about death, asking very concrete questions about what happens to one's body when it stops working. Death is personified as a separate person or spirit: a skeleton, ghost, angel of death, or bogeyman. Although death is perceived as final and frightening, it is not universal. Children in this age range begin to compromise, recognizing that death is final and real but mostly happens to older people (not to themselves). Grieving children can develop school phobias, learning problems, and antisocial or aggressive behaviors; can exhibit hypochondriacal concerns; or can withdraw from others. Conversely, children in this age range can become overly attentive and clinging. Boys may show an increase in aggressive and destructive behavior (e.g., acting out in school), expressing their feelings in this way rather than by openly displaying sadness. When a parent dies, children may feel abandoned by both their deceased parent and their surviving parent, since the surviving parent is frequently preoccupied with his or her own grief and is less able to emotionally support the child.

Ages 9 years and older

By the time a child is 9 years old, death is understood as inevitable and is no longer viewed as a punishment. By the time the child is 12 years old, death is viewed as final and universal.

In American society, many grieving adults withdraw into themselves and limit communication. In contrast, children often talk to those around them (even strangers) as a way of watching for reactions and seeking clues to help guide their own responses. It is not uncommon for children to repeatedly ask baffling questions. For example, a child may ask, "I know Grandpa died, but when will he

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come home?” This is thought to be a way of testing reality for the child and confirming the story of the death.

Grief and Developmental Stages Age	Understanding of Death	Expressions of Grief
Infancy to 2 years	Is not yet able to understand death.	Quietness, crankiness, decreased activity, poor sleep, and weight loss.
	Separation from mother causes changes.	
2–6 years	Death is like sleeping.	Asks many questions (How does she go to the bathroom? How does she eat?).
		Problems in eating, sleeping, and bladder and bowel control.
		Fear of abandonment.
		Tantrums.
	Dead person continues to live and function in some ways.	Magical thinking (Did I think something or do something that caused the death? Like when I said I hate you and I wish you would die?).
	Death is temporary, not final.	
	Dead person can come back to life.	
6–9 years	Death is thought of as a person or spirit (skeleton, ghost, bogeyman).	Curious about death.
		Asks specific questions.
		May have exaggerated fears about school.
	Death is final and frightening.	May have aggressive behaviors (especially boys).
		Some concerns about imaginary illnesses.
	Death happens to others; it will not happen to ME.	May feel abandoned.
9 and older	Everyone will die.	Heightened emotions, guilt, anger, shame.
		Increased anxiety over own death.
		Mood swings.
	Death is final and cannot be changed.	Fear of rejection; not wanting to be different from peers.
	Even I will die.	Changes in eating habits.
		Sleeping problems.
		Regressive behaviors (loss of interest in outside activities).
		Impulsive behaviors.
		Feels guilty about being alive (especially related to death of a brother, sister, or peer).

Issues for Grieving Children

There are three prominent themes in the grief expressions of bereaved children:

1. Did I cause the death to happen?

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2. Is it going to happen to me?
3. Who is going to take care of me?

Did I cause the death to happen?

Children often engage in magical thinking, believing they have magical powers. If a mother says in exasperation, “You’ll be the death of me,” and later dies, her child may wonder whether he or she actually caused the death. Likewise, when two siblings argue, it is not unusual for one to say (or think), “I wish you were dead.” If that sibling were to die, the surviving sibling might think that his or her thoughts or statements actually caused the death.

Is it going to happen to me?

The death of a sibling or other child may be especially difficult because it strikes so close to the child’s own peer group. If the child also perceives that the death could have been prevented (by either a parent or doctor), the child may think that he or she could also die.

Who is going to take care of me?

Because children depend on parents and other adults for their safety and welfare, a child who is grieving the death of an important person in his or her life might begin to wonder who will provide the care that he or she needs now that the person is gone.

Interventions for Grieving Children

There are interventions that may help to facilitate and support the grieving process in children.

Explanation of death

Silence about death (which indicates that the subject is taboo) does not help children deal with loss. When death is discussed with a child, explanations should be kept as simple and direct as possible. Each child needs to be told the truth with as much detail as can be comprehended at his or her age and stage of development. Questions should be addressed honestly and directly. Children need to be reassured about their own security (they frequently worry that they will also die or that their surviving parent will go away). A child’s questions should be answered, and the child’s processing of the information should be confirmed.

Correct language

Although it is a difficult conversation to initiate with children, any discussion about death must include proper words (e.g., *cancer*, *died*, or *death*). Euphemisms (e.g., “he passed away,” “he is sleeping,” or “we lost him”) should be avoided because they can confuse children and lead to misinterpretations.

Planning Rituals

After a death occurs, children can and should be included in the planning of and participation in mourning rituals. As with bereaved adults, these rituals help

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children memorialize loved ones. Although children should never be forced to attend or participate in mourning rituals, their participation should be encouraged. Children can be encouraged to participate in the aspects of funeral or memorial services with which they feel comfortable. If the child wants to attend the funeral (or wake or memorial service), it is important that a full explanation of what to expect is given in advance. This preparation should include the layout of the room, who might be present (e.g., friends and family members), what the child will see (e.g., a casket and people crying), and what will happen. Surviving parents may be too involved in their own grief to give their children the attention they need. Therefore, it is often helpful to identify a familiar adult friend or family member who will be assigned to care for a grieving child during a funeral.

Cross-cultural Responses

Grief, whether in response to the death of a loved one, to the loss of a treasured possession, or to a significant life change, is a universal occurrence that crosses all ages and cultures. However, there are many aspects of grief about which little is known, including the role that cultural heritage plays in an individual's experience of grief and mourning. Attitudes, beliefs, and practices regarding death and grief are characterized and described according to multicultural context, myth, mysteries, and mores that describe cross-cultural relationships.

The potential for contradiction between an individual's intrapersonal experience of grief and his or her cultural expression of grief can be explained by the prevalent (though incorrect) synonymous use of the terms *grief* (the highly personalized process of experiencing reactions to perceived loss) and *mourning* (the socially or culturally defined behavioral displays of grief).

An analysis of the results of several focus groups, each consisting of individuals from a specific culture, reveals that individual, intrapersonal experiences of grief are similar across cultural boundaries. This is true even considering the culturally distinct mourning rituals, traditions, and behavioral expressions of grief experienced by the participants. Health care professionals need to understand the part that may be played by cultural mourning practices in an individual's overall grief experience if they are to provide culturally sensitive care to their patients.

In spite of legislation, health regulations, customs, and work rules that have greatly influenced how death is managed in the United States, bereavement practices vary in profound ways depending on one's cultural background. When assessing an individual's response to the death of a loved one, clinicians should identify and appreciate what is expected or required by the person's culture. Failing to carry out expected rituals can lead to an experience of unresolved loss for family members. This is often a daunting task when health care professionals serve patients of many ethnicities.

Helping family members cope with the death of a loved one includes showing respect for the family's cultural heritage and encouraging them to decide how to commemorate the death. Clinicians consider the following five questions particularly important to ask those who are coping with the emotional aftermath of the death of a loved one:

1. What are the culturally prescribed rituals for managing the dying process, the body of the deceased, the disposal of the body, and commemoration of the death?
2. What are the family's beliefs about what happens after death?
3. What does the family consider an appropriate emotional expression and integration of the loss?
4. What does the family consider to be the gender rules for handling the death?
5. Do certain types of death carry a stigma (e.g., suicide), or are certain types of death especially traumatic for that cultural group (e.g., death of a child)?

Death, grief, and mourning are universal and natural aspects of the life process. All cultures have evolved practices that best meet their needs for dealing with death. Hindering these practices can disrupt the necessary grieving process. Understanding these practices can help clinicians to identify and develop ways to treat patients of other cultures who are demonstrating atypical grief. Given current ethnodemographic trends, health care professionals need to address these cultural differences in order to best serve these populations.

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Post-Test**

1. Almost all terminally ill individuals experience the same five sequential stages: denial, anger, bargaining, depression, and acceptance. (p. 5) A. True B. False
2. Clinical depression is often experienced by terminally ill patients; it is normal and typically resolves without treatment. (p. 6) A. True B. False
3. Which of the following is NOT an example of a dying trajectory? (p. 9-10)
 - A. Gradual slant
 - B. Peaks and valleys
 - C. Ascending slant
 - D. Descending plateaus
4. What are the five E's referring to? (p. 13)
 - A. Communication with patients and their family
 - B. Clinical steps used to evaluate patient status
 - C. Assessment of patient pain
 - D. Treatment parameters for terminally ill patients
5. Imparting information to the patient achieves which of the following? (p. 15)
 - A. Grants patients a sense of control
 - B. Reduces anxiety
 - C. Improves compliance
 - D. All of the above
6. Advance care planning is a process that helps patients identify and clarify their personal values and goals about health and medical treatment. (p. 20) A. True B. False
7. A _____ is a set of instructions based on likely scenarios of illness, goals for care, and specific treatments, combined with a general values statement. (p. 20-23)
 - A. living will
 - B. medical directive
 - C. health care proxy
 - D. will
8. Which of the following criteria is NOT utilized to determine patient decision-making capacity? (p. 26)
 - A. The patient must be able to understand the information.
 - B. The patient must use the information in a rational way to come to a decision.
 - C. The patient's decision must be consistent with the evidence-based advice presented by the medical community.
 - D. The patient must be able to appreciate the consequences of the decision.
9. A referral for hospice care becomes easier if the idea is presented as a response to a need rather than something to turn to when there is nothing left to do. (p. 28) A True B. False
10. Which of the following is NOT commonly seen when the primary goal of care is curative? (p. 30)
 - A. Patient's psychological attitude is "win."
 - B. Patient symptom relief is a primary focus.
 - C. Patient advance care planning is initiated.
 - D. Support for the family is addressed.

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11. Caring for a patient at home decreases the technical and emotional demands on the family.
(p. 33)
A. True B. False
12. In which phase of bereavement do individuals commonly experience a combination of intense separation anxiety and disregard or denial of the reality of the loss? (p. 37)
A. Shock and numbness
B. Yearning and Searching
C. Disorganization and Despair
D. Reorganization
13. Which of the following is NOT one of Worden's four tasks of grief? (p. 38-39)
A. Accepting the reality of the loss
B. Eliminating the pain of grief
C. Adjusting the environment in which the deceased is missing
D. Withdrawing emotional energy from the deceased and reinvesting in other relationships
14. Complicated grief can take many forms. It may manifest as absent grief, inhibited grief, delayed grief, conflicted grief, or chronic grief. (p. 39) A. True B. False
15. Anticipatory grief is defined as conventional (post-death) grief that begins early (pre-death).
(p. 42) A. True B. False
16. Which of the following is a sign of clinical depression? (p. 44)
A. Variable behavior
B. Pre-occupation with loss
C. Limited responsiveness to others
D. Periodic weeping or crying
17. The three phases of mourning are 1. The urge to recover the lost person. 2. Disorganization and despair. 3. Reorganization. (p. 45) A. True B. False
18. Children often play death games as a way of working out their feelings and anxieties in a relatively safe setting. (p. 48) A. True B. False
19. At what age do children typically understand that everyone (including themselves) will die? (p. 50)
A. 9 years and older
B. 6 - 9 years old
C. 2 - 6 years old
D. 0 - 2 years old
20. Euphemisms for death (e.g., "he passed away," "he is sleeping,") should be avoided with children because they can confuse them and lead to misinterpretations. (p. 51)
A. True B. False

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