

# **EPECTM-O**

**Education In Palliative And End-Of-Life Care For Oncology**

## **Self-Study Module 5: Survivorship**

## Module 5: Survivorship

Abstract .....	3
Introduction .....	3
Objectives .....	6
Quality of Survival .....	6
Importance of Symptom Management .....	6
Communicating with Patients Living with Recurrent or Advancing Cancer .....	9
Impact of Caring for Cancer Survivors on the Oncologist.....	12
Survivor Goals in the Incurable Cancer Continuum .....	13
The Family Caregiver as a Survivor .....	17
Summary .....	17
Appendix .....	19
References .....	25
Self-Assessment .....	28

## Abstract

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The term cancer survivor includes all people living with cancer. Whether designated cured, in remission, or living with known active cancer, patients who see themselves as survivors may better assume a proactively positive role rather than a passive victim role. Quality of life appears to be high for those with an excellent prognosis, although some tethers to the cancer experience can remain. For those facing active disease, coping mechanisms in the survival process are identified in this module, together with opportunities and communication approaches for the oncologist to facilitate such positive coping. The impact on oncologists and caregivers of caring for patients with cancer is also considered.

## Introduction

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This module will identify and briefly outline the considerable challenges to caring for cancer patients at varying points in their cancer experience. From the moment there is a confirmed cancer diagnosis, 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 cancer patient to focus fear into meaningful activity. (Ref. 1) (Ref. 2) (Ref. 3) These reluctant warriors are now cancer survivors. (Ref. 4) Oncologists who have chosen to care for and about cancer patients have answered a call that places them daily in the midst of high emotion and the drama of the human experience. The experience has the potential to enable oncologists to be more fully alive by surrounding themselves with people who most appreciate the precious gift of life.

A series of practical interventions is presented in this module to enable the oncologist to give patients and caregivers what they require while caring for him/herself in this highly charged and challenging environment. From diagnosis through cure or end-of-life support, there are many behaviors and attitudes the oncologist must manifest to maximize patient comfort, enhance respect for the patient and family, and encourage the patient and family to discover meaning throughout the trajectory of their experience. The oncologist is often personally transformed by accompanying patients and caregivers through the vicissitudes of managing a chronic, life-threatening illness.

The successes of the last decades in achieving cure and remission in oncology have generated a field of new clinical paradigms: those created by the side effects of successful antineoplastic treatment. Matters such as bleomycin-related pulmonary fibrosis, or radiation-related cognitive deficits, cardiac disease, or joint disease, or

infertility, are managed by oncologists and other specialists. Management approaches have reached the stages of consensus among experts in many cases and in some have an empirical research base as well.

## Module 5 - Video 1

### **Definition of survivor and dispositions toward cancer**

The National Coalition for Cancer Survivorship (NCCS) defines a cancer survivor as any person living with cancer at any time.

Inherent in this definition is the important transition of a cancer patient from victim to survivor. Although this definition serves to create a sense of belonging among the cancer patient community, the requirements of cancer patients are quite heterogeneous and incredibly sensitive to the disease process and its increasingly complex medical management. The oncologist is confronted with the need to support hope and optimism while having to remind patients that it is not possible to offer any guarantees as to the course of the disease. This ambiguity is seldom welcomed by the patient and family, who yearn for some sense of control in planning for the future.

The term survive has traditionally been used to refer to bereaved family as well, as in “[X] is survived by his sister and two nieces.” Since family and caregivers also survive the cancer experience both before and after the patient’s death, we do not restrict the term to patients. Rather, we attempt to be clear to whom the term refers in each setting that it is used.

### **Long-term remission and cure**

Among cancers with an excellent prognosis, quality of life appears to be high, suggesting that patients adapt well to their cancer experience. (Ref. 5) Survivors who live with cancers of poorer prognosis experience continuing stress. (Ref. 6) The quality of studies in this area, however, is still limited. (Ref. 7) Patients living after cancer may have tethers to their cancer experience that include things such as limited fertility, physical changes from surgery that impact self-image and function, altered life choices, or an altered sense of the future and what matters in life. See also EPEC™-O Module 4: Loss, Grief, and Bereavement for further treatment of this issue.

### **Survivorship for curable and noncurable patients**

Overall, cancer patients are living longer than in previous decades (5-year relative survival rate for all cancers is currently 63%) and are assuming a much more active role in their medical care. There are approximately 9 million cancer survivors in the United States and that figure is expected to increase as curative and life-prolonging advances continue and as the population continues to age. Progress in early detection and diagnosis, and the dramatic increase in the variety of clinical interventions have

significantly changed the landscape of managing cancer. Cancer is increasingly perceived to be a chronic illness. This is in stark contrast to the “death sentence” and stigma long associated with the diagnosis of cancer.

Along with this progress has also come added responsibility, and for many physicians added burdens. The general public is much better informed about the realities of cancer and is increasingly willing to openly discuss concerns related to diagnosis, treatment, and the possible outcomes of cure, remission, or even death. This maturing of the population and enhanced ability to discuss end-of-life concerns allows the oncologist to discuss, from the beginning of the relationship with the patient and family, goals of care, long-term planning, advanced directives, and hospice care. This sets the stage for ongoing honest discussion of the issues, and lets the patient know that there is always something that can be done to ease suffering, even if cure is not possible. See also EPEC™-O Module 1: Comprehensive Assessment.

The public’s expectations are not always realistic, and this can place a burden on the oncologist. The significant consumer movement, particularly in the United States, has demanded that patients and their family caregivers be actively involved in the decision-making process. Federal and state regulatory bodies have responded to the demands of advocacy groups and have recognized the rights of cancer survivors.

### **Specific concerns of cancer survivors**

There are a series of potential issues faced by cancer survivors that, if managed poorly, have great power to undermine the ability of cancer patients to maximize the benefit of medical treatments:

1. Lack of or inadequate health care insurance is a major problem for cancer patients, especially if they lose their jobs.
2. Job loss is particularly stressful for cancer patients and their family members given the costs related to health care. Although 80% of people with cancer return to work after a cancer diagnosis, the ongoing demands of prolonged treatments can put employment at significant risk.
3. Emotional concerns include the need to control fear, maintain optimism, and focus on the future. Specific manifestations of these concerns may include managing fear of cancer recurrence and death, buffering the impact of the disease on the family, and protecting oneself against loss of input into medical decision making should one become incapable of speaking for him/herself.
4. There is a lack of trained and licensed mental health providers for the large number of cancer patients who manifest high levels of distress and require these services, estimated to be between 33 and 47% in a general cancer population.
5. Fear of abandonment is a part of the human experience. Cancer is perceived by the patient as a personal assault that leaves the patient emotionally vulnerable. The experience can impact a person profoundly. Prolonged surveillance and

medical care stresses the patient, family, and social resources. The ability to attain dreams and aspirations are compromised, exacerbating fear, vulnerability and isolation. Abandonment fears are experienced by both patients and family caregivers.

6. Noxious physical symptoms create unnecessary suffering that grossly undermines the ability to cope and to trust in the health care team.

These issues should be raised as a part of the oncologist's comprehensive assessment—if not in the first interview, then as part of the continuous revision and updating of the comprehensive assessment that is part of optimal comprehensive cancer care. See also EPEC™-O Module 1: Comprehensive Assessment.

## Objectives

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The objectives of this module are to enable oncologists to:

- Define cancer survivor.
- Identify the specific challenges and barriers to the goals and aspirations of cancer survivors.
- Utilize practical interventions to actively support cancer patients at key points along the cancer continuum.

## Quality of Survival

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In a randomized, controlled study of sleep disturbances and other symptoms, women with metastatic breast cancer who also had pain, depression, bony metastases, or lack of social support had an increased risk over the control group for sleeping problems. (Ref. 8) This and similar studies support the importance of managing all forms of distress in people living with cancer. Researchers are creating helpful models to expand the biomedical model of care to include the psychosocial and spiritual spheres, and are finding evidence of their interaction. (Ref. 9) (Ref. 10) (Ref. 11) (Ref. 12)

## Importance of Symptom Management

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Advances in cancer discoveries and treatments are intended to serve what patients themselves experience within their social context. That is, quality of survival is paramount: symptom control, respectful care, the opportunity to maintain a role within

the social system with minimal erosion of self-control, and the ability to make a meaningful contribution.

Although cancer survivors are not always able to adequately judge the quality of their cancer treatments, they are exquisitely aware of the quality of their lives. Without adequate management of the basic physical needs of the patient, there can be no meaningful quality of survival. See also EPEC™-O Module 3: Symptoms.

The physical experience is a screen through which all other perceptions are filtered. Significant physical distress exacerbates but also masks all other concerns of patients. It is not until physical distress (i.e., pain, delirium, nausea, etc.) is managed that other concerns (i.e., anxiety, depression, sadness, search for meaning, etc.) can be addressed. There is a direct relationship between the physical and psychosocial distress of the patient and the psychological impact on the family caregiver. See also EPEC™-O Plenary 2: Models of Comprehensive Care, and EPEC™-O Module 1: Comprehensive Assessment.

Clinical experience also tells us that there is an essential connection between the quality of life of cancer survivors and of their professional caregivers. Health care professionals, who have committed themselves to the relief of suffering, have difficulty feeling powerless in the face of suffering.

## Module 5 - Video 2

### **Managing psychosocial distress in the cancer survivor**

The oncologist has a unique and powerful role in helping the patient to find meaning in the cancer experience. The oncologist and his or her support team are the only professional support system for most patients. The oncologist sets the emotional tone for the team and for the patient. The oncologist also sets the content boundaries. For example, if the patient is asked about the effectiveness of his or her coping strategies along with the medical information, the patient and family will know that this topic can be comfortably shared with the oncologist.

Cancer erodes self-concept and confidence so patients and their family caregivers may be highly attuned to further challenges to their sense of control and predictability. When patients do not feel respected, their sense of threat is significantly increased and a lack of trust ensues. People feel respected when they are given adequate time to tell their story, are involved in decision making, feel heard and deeply understood, and are seen within their social context as still making a meaningful contribution.

The oncologist can prompt the patient in making meaning of his or her experience by asking questions, such as:

- “What impact has this illness had on your life?”

- “What impact has the illness had on the lives of your loved ones?”
- “How do you see this illness in relation to the rest of your life?”
- “Have you been able to gain any benefit from this difficult experience?”
- “Have you been able to learn anything about yourself from this experience that you did not know before?”
- “How would you like to handle this part of your life?”

Although the oncologist can facilitate survivors’ adaptation to their illness with some of the above types of questions, in the face of acute or prolonged psychosocial distress a referral to a licensed mental health professional should be made in a timely manner. Despite data that demonstrate that 30 to 47% of cancer patients have high levels of psychosocial distress, it is estimated that only about 10% of patients receive mental health counseling as a result of a cancer diagnosis and resulting treatment—a number that is lower than some recent estimates of general population use of mental health services. The oncologist is in a unique position to teach patients and their family caregivers about the utility of mental health services and how best to access them. For most patients, cancer will be the hardest problem they will ever have to face, and early counseling may be effective in preventing longer-term sequelae. (Ref. 13) There are also practical benefits to the oncologist in being able to share the support of patients or family caregivers who benefit from psychosocial counseling.

The National Comprehensive Cancer Network (NCCN) has developed a practical guideline for oncologists to use in identifying and referring cancer patients for treatment of psychosocial distress. (Ref. 14)

## **The importance of the emotional environment**

The oncologist can use counter-transference (the feelings he or she experiences when in the presence of a particular patient) as a cue to what the patient is experiencing. Emotional responses are both the connective tissue and glue of human relationships. Bonds are innately built on emotions—not facts. Acceptance, fear, love, isolation, a sense of connectedness, and rejection are all common responses to a diagnosis of cancer. The oncologist’s ability to welcome and use these experiences to benefit the patient and caregivers will actually enhance his or her own sense of human connectedness, control, and gratification. However, a pattern of avoidance and distancing from these core human experiences can be quite dissembling, resulting in isolation and eventual burnout. See also EPEC™-O Module 15: Cancer Doctors and Burnout.

Experimental evidence increasingly demonstrates the impact of psychological stress on measurable physiologic responses. For instance, stressful life events are associated with a higher incidence of cutaneous sensory symptoms. (Ref. 15) Family members of patients undergoing bone marrow transplantation have been shown to experience both

psychological and immunological reactions. (Ref. 16) These physiologic responses to psychological stress can be either helpful or harmful to the person experiencing them.

## **Communicating with Patients Living with Recurrent or Advancing Cancer**

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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 cancer.
- 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 response

Although it seems odd to think of dying cancer 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 cancer survivors 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. The oncologist should be actively supportive of this effort.

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 cancer 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; and receive the best medical and psychosocial care possible until they die.

### **Oncologists' contributions to survivor goals**

The oncologist has a pivotal role in supporting the dying patient and his or her family. The oncologist must reassure the patient and family that all that could be done was in fact done; that the patient and family will not be abandoned by the oncologist; that even if there is a transfer to another team to manage the death, the oncologist will still be available to answer any lingering questions; and that the patient's physical and psychosocial concerns will be attentively managed. Oncologists should also reassure the family that after the death, they will still be available to answer any questions. A follow-up telephone call or note within 1 month of the patient's death is an important opportunity for the oncologist to assess the family's adjustment to the death and for the oncologist to express his or her condolences. (Ref. 17) Families greatly value this

closing contact, even if it is only 5 to 10 minutes in duration. See EPEC™-O Module 4: Loss, Grief, and Bereavement.

## **Impact of Caring for Cancer Survivors on the Oncologist**

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Physical demands, “cheerleader” fatigue, lack of adequate time with patients and for themselves, self doubt, guilt, shame, frustration, and distress are frequently experienced by oncologists caring for cancer survivors, especially those with disease that is poorly controlled. The physical and intellectual demands on oncologists come from many directions and can be relentless: reimbursement increasingly drives health care with ever-changing rules and regulations resulting in decreased funding; medical care is increasingly specialized and complex; patients and their family members are assertive in their request for physician face-time in environments that demand that more patients be seen more “efficiently.” Given that oncologists perceive a significant absence of adequate supportive services available to their patients and that only 20% experience caring for dying patients as “highly meaningful,” it is understandable that watching some people deteriorate over time can be an especially unpleasant ordeal for many oncologists. In a survey of over 100 identified putative pain experts in southeastern Virginia, most of whom had over 10 years of clinical experience, only 9% of these physician experts received any formal education in caring for patients requiring palliative care services. Lack of training and perceived skill deficits create a sense of lack of control, avoidance of emotional content, and distress among clinicians.

Because patients and family caregivers experience the medical visit as highly valued, concentrated, and very brief, the emotions manifested at the visit are intense and the oncologist may experience the patient and family as more distressed than they would be in their natural setting. This can result in psychic exhaustion for the oncologist and his or her staff. In the absence of adequate gratification and meaning, long hours of clinical care and great physical demands are a prescription for demoralization and burnout.

Self care is essential if the oncologist is to have a sustainable career. These matters are further considered in EPEC™-O Module 15: Cancer Doctors and Burnout.

### **When patients die**

Although survivorship and palliative care may seem to be mutually exclusive, in fact, medical care for people with chronic, life-threatening illness, even when considered controllable or cured, is still primarily palliative in nature. Unwelcome physical changes, persistent emotional distress, and ongoing surveillance all require careful vigilance and intervention by the oncologist. It was once considered a truism that it was relatively simple to predict the demise of patients with advanced cancers. However, due to recent improvements in disease-directed treatment and symptom management, patients experience a better quality of life and longer survival.

As a result, oncologists, during the course of treating patients, are developing longer-term relationships with patients and their family members. Although this is generally very gratifying, oncologists are in need of new and better skills to understand the changing needs of patients and families throughout the care continuum. The needs of each patient and family, as they strive to manage and make sense of their situation, are unique. These extended relationships may have a tendency to become more intense, causing complex psychosocial interactions between patients and their professional caregivers. In this setting, oncologists are vulnerable to self-doubt about the helpfulness of offered treatments, and may experience guilt over not being able to magically remove the suffering inherent in the disease process.

The wish to control the dying process (with its multilevel connections to the supernatural and the spiritual) is strong for patients, family caregivers, and oncologists. Patients may frequently overestimate the ability of the oncologist to control life and may imbue the oncologist with magical shamanistic-like powers. When dying is elusive and distress is elevated, the wish to control is instinctively activated and increased. Health care professionals have a high level of need to control. The pressure on the oncologist to join in this magical thinking can be quite seductive and disarming, especially in the absence of adequate self-awareness.

## **Survivor Goals in the Incurable Cancer Continuum**

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Goals of care change as the cancer course progresses. (Ref. 18) These matters are also dealt with in EPEC™-O Module 9: Negotiating Goals of Care. The Appendix provides a summary of the impact of cancer along the disease continuum for the patient. (Ref. 19)

### **Diagnosis, treatment, remission, recurrence, or progression**

The cancer continuum is composed of a series of often predictable events experienced by patients. (Ref. 20) For our discussion, the categories are divided into diagnosis, treatment, remission, recurrence or progression, advanced disease, and care at the end-of-life. Any cancer-related event is experienced as stressful to the patient, even a declared cure. 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 cancer 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. (Ref. 1) (Ref. 2) (Ref. 21) Finding an oncologist, 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.

**Survivor goals:** The goal of the cancer survivor at diagnosis is to find the best medical care possible while minimizing disruption to life.

**Oncologists' contribution to survivor goals:** A clearly defined plan of action, availability, and emotional support are what the newly diagnosed cancer patient needs most. Being available means providing information, explanation and re-explanation, support, resources, and referrals, if requested. The oncologist can help the cancer survivor 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 (Surgery, chemotherapy, radiation)

**Patient response:** Cancer treatments have significantly improved in the last 25 years, but most patients and the general public still harbor exaggerated fears about its toxicities. Surgeries have become less disfiguring. Radiation therapy doses have decreased. The side effects of chemotherapy are much better managed. However, many cancer survivors still say that coping with treatment is harder than coping with the reality of having cancer. Physical disfigurement, infertility, chronic pain, early menopause, alopecia, and anxiety are still common experiences.

**Survivor goals:** The goal of the cancer survivor during treatment is primarily to complete treatment. Other cancer survivor 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.

**Oncologists' contribution to survivor 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.

**Survivor goals:** The goal of the cancer survivor at remission is to redefine what a normal life is for them now, given their cancer 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 oncologist. It is a challenge for the survivor to cope with inevitable changes within the family structure and social network, to resume intimacy with their loved ones, now as a cancer survivor, and most of all to give some meaning to their cancer experience as part of a life still being lived.

**Oncologists' contribution to survivor goals:** Celebrating remission and managing fear of recurrence are always concerns for patients, and the oncologist 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. (Ref. 22) 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 oncologist. 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. There is some potential for the oncologist to feel pulled between the needs of both. 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.

Ultimately, patients and families can usually be helped toward finding a different source of optimism and hope that is within realistic range for their circumstances. (Ref. 23)  
(Ref. 24)

**Survivor goals:** The goal of cancer survivors within the context of recurrence or advancing disease is to maximize a sense of personal control by understanding the cancer 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. Cancer survivors 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.

**Oncologists' contribution to survivor 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 told by the oncologist that it is the treatment that has failed, not the patient or the oncologist. When the limits of human capacity are openly acknowledged, there is the potential for a deeper human connection between the patient and physician.

The oncologist 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 in his or her cancer experience. The oncologist 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.

Caring for the complex and constantly changing needs of cancer survivors is difficult under any circumstances, but when the patient does not respond favorably to treatment, unique challenges for the oncologist emerge. For the oncologist who perceives that the only acceptable goal is cure, it is not an exaggeration to say that he or she goes through a process parallel to the one experienced by the patient and family caregivers. Each time a patient dies, the oncologist is confronted with the limits of intervention and the feeling that the cancer has unfortunately “won” again. We have all heard the refrain, “Don’t bet against cancer.”

The oncologist may also perceive the impending death of a patient due to cancer as an assault on his or her sense of self-worth. Cumulative losses can have a devastating impact on the ability to function effectively and feel connected to others. Despite the physician’s position of sitting at the top of the clinical health care hierarchy, feelings of inadequacy inherent in caring for the dying put the oncologist at great risk for personal distress. See also EPEC™-O Module 15: Cancer Doctors and Burnout.

## **The Family Caregiver as a Survivor**

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Much of the above discussion has mentioned the importance of the family caregiver, as seen from the perspective of the patient. The caregiver is also transformed by the experience of the patient’s cancer and often performs heroic tasks in a role that is better suited to the designation of survivor than one that implies passive reception of a victimizing circumstance.

These challenges are addressed in EPEC™-O Module 4: Loss, Grief, and Bereavement. A growing literature on caregiver burden and caregiver gratification and growth is available elsewhere. While beyond the scope of this curriculum, the oncologist will want to be familiar with this field, both because of the importance of the caregiver to the patient and because caregivers are at increased risk of becoming patients as compared with matched controls. (Ref. 25) (Ref. 26) (Ref. 27) (Ref. 28)

## **Summary**

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The number of cancer survivors is increasing and includes not only those who have achieved remission or cure but also all patients living with cancer from diagnosis through death. The psychosocial aspects of cancer survivorship have been underappreciated. Attention to these issues is essential across the continuum of

oncology care. The Appendix Table provides a summary of the impact of cancer along the disease continuum for the patient. (Ref. 19) Quality of survival is paramount, symptom control, respectful care, the opportunity to maintain a role within the social system with minimal erosion of self-control, and the ability to make a meaningful contribution.

The successes of the last decades in achieving cure and remission in oncology have generated a field of new clinical paradigms—those created by the side effects of successful treatment. Matters such as bleomycin-related pulmonary fibrosis, or radiation-related cognitive function, cardiac disease, or joint disease, or infertility, are managed by oncologists and other specialists. Management approaches have reached the stages of consensus among experts in many cases, and in some have an empirical research base as well.

### **Pearl**

1. Make a partnership with your patient and the family caregiver; draw them into the interdisciplinary team and foster their active participation in the care plan.

## Appendix

### Crisis Impact

Crisis	Cancer Survivor Responses	Survivor Goals	Oncologist Supporting Survivor
<b>Diagnosis</b>	Fear Anxiety Numbness Denial Confusion Confronting mortality Anger Questioning trust in God, self, one's body, others	Clarify health insurance Engage an oncologist Have best care possible with the least disruption to life Manage work situation	Clearly defined plan of action Physical availability Information Support Education Resource provision Mental health referral, if high or unabated distress Advocacy Exquisite management of physical symptoms

Crisis	Cancer Survivor Responses	Survivor Goals	Oncologist Supporting Survivor
<b>Treatment (Surgery, Chemotherapy, Radiation)</b>	Dread Fear/Anxiety Depression Agitation Confusion Need to control Sense of purpose Confronting changes in one's body Fear of intimacy and sexual contact Nausea and vomiting Anticipatory nausea Avoidance Vulnerability Pain	Get through treatment Maximize benefits of treatment Cope with the side effects Optimize independence and control Protect insurability, employment Strive to maintain normalcy Keep family life as normal as possible	Provide a clear plan of action Anticipate and work to minimize the unpleasant side effects of treatment Have exquisite management of physical symptoms Support the patient's optimism and perseverance Refer to mental health professional for cognitive-behavioral coping skills

Crisis	Cancer Survivor Responses	Survivor Goals	Oncologist Supporting Survivor
<b>Remission</b>	<p>Relief</p> <p>Gratitude</p> <p>Dodging a bullet</p> <p>Hypervigilance over health</p> <p>Fear of recurrence</p> <p>Obsessive thoughts</p> <p>Loneliness</p> <p>Anger</p> <p>Exerting control</p> <p>Altruistic bargaining</p> <p>Search for meaning</p> <p>Fear</p> <p>Anxiety</p>	<p>Rehabilitation: psychological and physical, cognitive, restoration of self-worth</p> <p>Image recovery</p> <p>Managing emotions around fear of recurrence</p> <p>Refocusing on work and family life</p> <p>Redeveloping intimacy</p>	<p>Maintaining a scheduled set of follow-up visits</p> <p>Exquisite management of physical symptoms</p> <p>Supporting psychosocial rehabilitation</p> <p>Providing emotional support</p> <p>Referral should be made to a peer support group, if requested</p> <p>If distressed, referral to mental health professional</p>

<b>Crisis</b>	<b>Cancer Survivor Responses</b>	<b>Survivor Goals</b>	<b>Oncologist Supporting Survivor</b>
<b>Recurrence or New Primary Cancer</b>	Loss of control Anger Fear Depression Anxiety Shock Loss of hope Denial Guilt Loss of trust Feelings of alienation Increased vulnerability Confronting mortality Search for meaning	Maximize a sense of personal control Maintain self-worth Create skills to manage emotions Integrate reality of illness and family implications Control fear of death	Delineating the next steps Exquisite management of physical symptoms Assuring that the patient will never feel abandoned Encouraging a family meeting Physical ability Honesty, information, hope, and support Referral for supportive psychotherapy or cognitive-behavioral skills training

Crisis	Cancer Survivor Responses	Survivor Goals	Oncologist Supporting Survivor
<b>Advancing Disease</b>	Depression Anxiety Demoralization Fear Denial Anger Fear of intimacy	Dignity Direction in life Maintenance of role in work, family, family, and community Management of guilt about being a burden Making a contribution Control of fears of abandonment	Exquisite management of physical symptoms Family meeting request Physical availability Redefinition of goals of treatment Encouragement of the search for meaning Honesty, information, hope, and support Reassuring the patient and family that all could be done was in fact done Hospice referral Emotional support Referral for cognitive-behavioral skills training, supportive psychotherapy, or spiritual counseling, as appropriate Referral to psychiatry for clinical depression

Crisis	Cancer Survivor Responses	Survivor Goals	Oncologist Supporting Survivor
<b>End-of-Life</b>	Isolation Frustration Depression Fear Anxiety Denial Demoralization Self-destructive behavior Loss of control Guilt Anger Fear of abandonment Increased dependency Acceptance Withdrawal Search for meaning in past as well as present Pain/suffering Need to discuss afterlife	Dignity Being surrounded by family Control of fears of abandonment Management of guilt about being a burden Making a contribution	Hospice assumes primary responsibility for ongoing care Commitment to remain available in new role Periodic contacts with patient and family Follow-up bereavement call to family Reassuring the family that all that could be done was in fact done

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## Self-Assessment

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### Module 5: Survivorship

1. The National Coalition for Cancer Survivorship (NCCS) defines a cancer survivor as “any person living with cancer at anytime.”

- a). true
  - b). false
- 

2. Melinda Bennett had stage II breast cancer treated with lumpectomy, local radiation, and chemotherapy with adriamycin and paclitaxel. She is now 1 year out from completing treatment. Her emotional concerns at this time are likely to include:

- a). fear of recurrence and death
  - b). desire to disconnect from her cancer treatment team
  - c). feeling she is now “cured” of her cancer
  - d). feeling her family has forgotten her cancer experience
- 

3. For Mrs. Bennett, the most likely source of professional support will be:

- a). a designated mental health professional
  - b). a support group
  - c). her oncologist and office staff
  - d). her religious pastor
- 

4. For Mrs. Bennett, her oncologist can explore her cancer experience by saying:

- a). “Have you noticed any swelling in your armpit?”
  - b). “What impact has this illness had on your life?”
  - c). “Have you had any pain?”
  - d). “How are you feeling?”
-

## Self-Assessment Answers

**Question 1.** The correct answer is: **a)**

**Question 2.** The correct answer is: **a)**

Emotional concerns generally involve controlling fear, maintaining optimism, and focusing on the future and are specifically manifested in relating to the health care team and managing fear of recurrence and death.

**Question 3.** The correct answer is **c)**

The oncologist, and his or her support team, will be the only professional support system for most patients.

**Question 4.** The correct answer is: **c)**

The oncologist can prompt the patient in making meaning of the experience by asking questions, such as: “What impact has this illness had on your life? What impact has the illness had on the lives of your loved ones? How do you see this illness in relation to the rest of your life? Have you been able to gain any benefit from this difficult experience?”