

EPEC-O

Education in Palliative and End-of-life Care - Oncology

Participant's Handbook

Module 5

Survivorship

Emanuel LL, Ferris FD, von Gunten CF, Von Roenn J.
EPEC-O: Education in Palliative and End-of-life Care for Oncology.
© The EPEC Project,™ Chicago, IL, 2005

ISBN: 0-9714180-9-8

Permission to reproduce EPEC-O curriculum materials is granted for non-commercial educational purposes only, provided that the above attribution statement and copyright are displayed. Commercial groups hosting not-for-profit programs must avoid use of EPEC-O materials with products, images or logos from the commercial entity.

The EPEC Project™ was created with the support of the American Medical Association and the Robert Wood Johnson Foundation. The EPEC-O curriculum is produced by The EPEC Project™ with major funding provided by the National Cancer Institute, with supplemental funding provided by the Lance Armstrong Foundation. The American Society of Clinical Oncology partners with the EPEC-O Project in dissemination of the EPEC-O Curriculum. Acknowledgment and appreciation are extended to Northwestern University's Feinberg School of Medicine, which houses The EPEC Project.

Special thanks to the EPEC-O Team, the EPEC-O Expert Panel, and all other contributors.

Accreditation Statement

The Northwestern University Feinberg School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

Visit www.epec.net to order EPEC materials, access On-line Distance Learning, or for further information.

Contact EPEC by E-mail at info@epec.net, or

The EPEC Project™
750 N. Lake Shore Drive, Suite 601
Chicago, IL 60611
USA

Phone: +1 (312) 503-EPEC (3732)

Fax: +1 (312) 503-4355

Abstract

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 pro-actively 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.

Key words

Cancer survivorship, cancer continuum, cure, remission, psychosocial distress, challenges to coping, caregivers, professional self-care

Objectives

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.

Clinical case on trigger tape

R.J. is a 55-year-old who underwent a radical prostatectomy for prostate cancer. He continues to have routine follow up visits with his physician. Recently he has been experiencing difficulty regaining his pre-cancer quality of life.

Introduction

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 on, 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 to them. Yet there is courage in accepting a challenge that is deeply ingrained in the human spirit that is able to focus fear into meaningful activity.^{1,2,3} For these reluctant warriors are now cancer survivors.⁴ For the oncologists who have chosen to care for and about cancer patients, they answered a call which is always emotional and dramatic. They have taken the risk to

be more fully alive by surrounding themselves with people who most appreciate the precious gift of life.

A series of practical interventions to give patients and caregivers what they require and how to care for you in this highly charged and challenging environment are discussed. From diagnosis through cure or end-of-life support, there are many behaviors and attitudes the oncologist must manifest to maximize comfort, enhance respect, and encourage the discovery of meaning. By accompanying patients and caregivers through the vicissitudes of managing a chronic life-threatening illness, the oncologist is inevitably transformed by the experience.

The successes of the last decades in achieving cure and remission in oncology has generated a field of new clinical paradigms: those created by the side effects of successful anti-neoplastic 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. The EPEC-O Curriculum will include treatment of these survivorship issues in its next version of the curriculum, expected in late 2005.

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 anytime*.

Inherent in this definition is the important transition of 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.⁵ Survivors who live with cancers of poorer prognosis experience continuing stress; eg, breast cancer survivors with persistent fatigue have altered cortisol responses to stress.⁶ The quality of studies in this area, however, is still limited.⁷ Patients living after cancer may have tethers to their cancer

experience that may include things such as limited fertility, physical changes from surgery that impact self-image and function, altered life choices, or an altered sense of their 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 non-curable patients

Overall, cancer patients are living longer than in previous decades (five-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, 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 their concerns, from diagnosis through cure, and more recently about their dying. This maturing of the population and enhanced ability to discuss end-of-life concerns removes the primary barrier to oncologists discussing goals and longer-term planning, including advance care planning, generally, and hospice specifically, *at the beginning* of the relationship with the patient and their loved ones. This informational-seeding opens the conversation now for an 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.

That the public’s expectations are not always realistic can be a specific 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 psychosocial aspects to cancer survivorship that may be under-appreciated in that, if managed poorly, they have great power to undermine the ability of cancer patients to maximize the benefit of medical treatments:

1. Lack of or under health care insurance is a major problem for cancer patients especially if they lose their job.
2. Job loss is particularly stressful for cancer patients and their family members given the costs related to health care. Although eighty percent 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 generally involve controlling fear, maintaining optimism, and focusing on the future and is specifically manifested in relating to the health care team, managing fear of recurrence and death, buffering the impact on family, and protecting oneself against losing the ability to influence how medical care will be provided if the survivors become incapable of speaking for themselves.
4. Lack of trained and licensed mental health providers for the large number of cancer patients who manifest high distress and require these services, estimated to be between 33-47% in a general cancer population.
5. Fear of abandonment is a constant in all human experience. Cancer is always deeply experienced as a personal assault and as social exposure of vulnerability that impacts people at their very core. Prolonged surveillance and medical care stresses the patient, family, and social resources. The ability to attain dreams and aspirations are compromised thereby greatly enhancing the primal fear of exposure and of being alone. 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.

Quality of survival

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.⁸ This and similar studies support the importance of managing all forms of distress in people living with cancer. Researchers are creating helpful models for expansion of the biomedical model of care to include the psycho-social and spiritual spheres, and finding evidence of their interaction.^{9,10,11,12}

The importance of symptom management

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 in 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. Few health care professionals tolerate feeling powerless in the face of suffering well, especially those who have committed themselves to its relief.

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 their support team, will be 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 their coping along with their medical information, the patient and family will know that this is a topic that 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 when they are seen within their social context as still making a meaningful contribution.

The oncologist can prompt the patient in making meaning of their 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' adapting 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 30-47% 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 the patient and their family caregivers about the utility of mental health services and how to best access them. For most people, cancer will be the hardest problem they will ever have to face, and early counseling may be effective in preventing longer term sequelae.¹³ There are also many 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 to identify and refer cancer patients for treatment of psychosocial distress.^{14, 15}

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 about 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 the sense of human connectedness, control, and gratification experienced by the oncologist him/herself. However, a pattern of avoidance and distancing from these core human experiences can be quite dissembling resulting in isolation and eventual burn out. See also EPEC-O Module 15: Cancer Doctors and Burnout.

For family caregivers, magical thinking around cure or the preconscious or even openly acknowledged desire for a 'more timely death, already' may build on existing survivor guilt and shame. Every family has well established hierarchy, defenses, and ways of communicating. Highly charged emotional environments, such as dying, quickly expose the underpinnings of the family system to the oncologist. This unfolding may also enable the oncologist to become more aware of their own ways of managing the demands of a challenging professional and personal life. Self-awareness and a balanced life significantly enhance the ability to tolerate the unrealistic demands of a professional life while finding meaning in daily activities.

Evidence of the relationship between psychological stress and the hypothalamic pituitary axis and other somatic stress mediators and physiological responses such as in the skin exists.¹⁶ Some evidence exists that psychological and immunological reactions of family

members, for instance to patients undergoing bone marrow transplantation, also correlate and can exhibit helpful or unhelpful trends.¹⁷

Communicating with patients living with recurrent or advancing cancer

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 live a meaningful life.
- 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. You will *never* abandon them—*Ever*.
- Tell the truth and give complete answers and that you expect them to do the same.
- Strive for exquisite management of their physical and psychosocial symptoms at all times and that they will actively participate in agreed upon plans of care.
- Offer all other reasonable options if adequate symptom management ever becomes a significant problem.
- 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, social workers, psychologists, psychiatrist, 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 that 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 will be stirred up as the patient and family begin to actively mourn their impending losses. As importantly as to grieving for what is actually being lost, there will also be losses experienced for relationships that they wished they had but did not. 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 that they have been through and yet they are still dying. 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 their 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 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 disconnected-ness 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 be significantly shortening their life, there is a period of disbelief, 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 can still have some control and influence over at least some of their concerns. No person does well in life when they are adrift. Dying persons have worth and the ongoing responsibility to make a contribution beyond their past on many levels: How they teach the next generation to die in a meaningful way, to resolve conflicts with loved ones, to demonstrate love for others and to 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 to 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 in 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, treated in a respectful manner, and to receive the best medical and psychosocial care possible until they die.

Oncologists' contribution to survivor goals

The oncologist has the most pivotal role, outside of the family, in supporting the dying patient and their 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; 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 one month of the patient's death is an important opportunity for the oncologists to assess the family's adjustment to the death and for the oncologists to express their condolences.¹⁸ Families greatly value this closing contact, even if it is only 5-10 minutes in duration.

Impact of caring for cancer survivors on the oncologist

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 are 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 quite 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 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 skills deficits create a sense of lack of control, avoidance of emotional content, and distress in the clinician.

The oncologist may be inundated with the demands of caring for acutely ill patients within the context of an emotionally charged environment where the oncologist is ultimately seen as the final authority. When treatment is prolonged, levels of denial, anger, frustration, and magical thinking are ubiquitous and fall upon the oncologist to carefully balance conflicting human impulses, many outside of conscious awareness of all involved. Caring for cancer survivors is always hard work even within the context of highly satisfying relationships. This situation becomes even more difficult as some patients, confused by the dependence on their physician for survival, imbue them with wisdom well beyond their scope of practice. This level of potential seduction is exhausting for the physician and inherently disappointing for the patient.

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 their staff. In the absence of adequate gratification and meaning, long hours of clinical care and great physical demands are a prescription for demoralization and burn out.

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 in 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 are confronted with patients and family members who they care for over the course of many years. Although this is generally very gratifying, there is also a need to better understand the changing needs throughout the care continuum. For the needs are very different as patients, accompanied by their family caregivers, strive to manage and make sense of their situation. This extended relationship may become more intense, causing complex psychosocial reactions in patients and their caregivers with potent implications for the mental health of the oncologist; primarily, resulting in self-doubt that what is being provided is helpful, and 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 the oncologist. 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 non-curable cancer continuum

Goals of care change as the cancer course progresses.¹⁹ These matters are also dealt with in EPEC-O Module 9: Negotiating Goals of Care. Table 1 provides a summary of the impact of cancer along the disease continuum for the patient.²⁰

Diagnosis, treatment, remission, recurrence or progression

The cancer continuum is composed of a series of often predictable events experienced by patients.²¹ 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, feel a lack of control and predictability, frustration, and anger. Depression (10% prevalence in Americans over the course of a lifetime 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 the next steps.^{22,1,2} 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-control 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 is what the newly diagnosed cancer patient needs most. By being available means to provide information, explanation and re-explanation, support, resources, and referrals, if requested. The oncologist can help the cancer survivor to focus on next steps and this will help to focus the energy of the emotional reactions. For those patients who cannot get focused on the 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. Many cancer survivors still say that coping with treatment was harder than coping with the reality of having cancer. Physical disfigurement, infertility, chronic pain, early menopause, alopecia, and anxiety are still very 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 the 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 (ie, transportation, financial assistance) and referral information for psychosocial support (ie, 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: The patient response to remission is usually one of having a second chance. They feel like they have dodged a bullet and are 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. Hyper-vigilance and some degree of hypochondriasis are to be expected. The further the patient gets from treatment the more their distress will decrease. If distress does not decrease over time, this requires an intervention.

Survivor goals: The goal of the cancer survivor at remission is to redefine what a *normal* life is for them now, given their cancer experiences. Psychosocial rehabilitation is central to this effort. Fear of recurrence is always a shadow on every victory. Re-investing 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 their 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 lived, and still living.

Oncologists' contribution to survivor goals: Celebrating remission and helping to manage fear of recurrence is always a concern for patients so the oncologist can help the patient to focus on the future and to lay out the next steps. By maintaining a *scheduled set of visits*, the patient's anxiety about separation from the person who treated them will be reduced significantly. About two months after treatment is completed, the full impact of physical changes, vulnerability, and what the patient 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.²³ Guilt and shame may also be present as the patient may feel some responsibility for what is happening to them. The

patient may feel that they have let down the family and their oncologist. Lack of control—fears about physical deterioration and death—will surface. Concerns about the impact on loved ones will be significant. Intellectual constructs about 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 the disease.

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 patients 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 who 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 circumstance.^{24,25}

Survivor goals: The goal of the cancer survivor 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. That is, 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. The context of which is manifested by focusing the energy necessary to cope with the chronicity and uncertainty related to additional treatment and the disease while still making a contribution at home and work.

At recurrence of advancing disease, it is important that the patient be told by the oncologist that the treatment has failed, not the patient or the oncologist. To openly acknowledge the limits of human capacity, there is the potential for a deeper human connection between the patient and physician.

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 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.

Oncologists' contribution to survivor goals: Recurrence and advancing disease is marked by the patient's experience that the 'last shoe has dropped.' The oncologist can best support the survivor's goals by clearly delineating the next steps, a plan of action to manage the medical challenges, and by 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 a referral to peer support groups, a referral to a mental health professional should also be offered.

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 there is a parallel process experienced by the patient and their family caregivers. Every time a patient dies the oncologist is confronted with the limits of intervention and 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 from cancer as an assault of their sense of self worth. Cumulative losses can have a devastating impact on the ability to function effectively and to 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

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 cancer in the patient 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.

The challenges are partly treated 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.^{26,27,28,29} Materials for use by caregivers are provided as a companion to the EPEC-O Curriculum (www.epec.net).

Summary

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 under appreciated. Attention to these issues is essential across the continuum of oncology care. Table 1 provides a summary of the impact of cancer along the disease continuum for the patient.²⁰ 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 has generated a field of new clinical paradigms: those created by the side effects of successful anti-neoplastic 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. The EPEC-O Curriculum will include treatment of these survivorship issues in its next version of the curriculum, expected in late 2005.

Appendix

Crisis Event	Cancer Survivor Responses	Survivor Goals	Oncologist Supporting Survivor
Diagnosis	<p>Fear</p> <p>Anxiety</p> <p>Numb</p> <p>Denial</p> <p>Confusion</p> <p>Confronting mortality</p> <p>Anger</p> <p>Question trust in God, in self, in one's body, others</p>	<p>Clarify health insurance</p> <p>Engage an oncologist</p> <p>Best care possible with the least disruption to life</p> <p>Manage work situation</p>	<p>Clearly defined plan of action</p> <p>Physical availability</p> <p>Information</p> <p>Support</p> <p>Education</p> <p>Resource provision</p> <p>Mental health referral, if high distress or unabated</p> <p>Advocacy</p> <p>Exquisite management of physical symptoms</p>
Treatment (Surgery, Chemotherapy, Radiation)	<p>Dread</p> <p>Fear/Anxiety</p> <p>Depression</p> <p>Agitation</p> <p>Confusion</p> <p>Need to control</p> <p>Sense of purpose</p> <p>Confronting changes in one's body</p> <p>Fear of intimacy and sexual contact</p> <p>Nausea and vomiting</p> <p>Anticipatory nausea Avoidance</p> <p>Vulnerability</p> <p>Pain</p>	<p>Get through treatment</p> <p>Maximize benefits of treatments</p> <p>Coping with the side effects</p> <p>Optimize independence and control</p> <p>Protect insurability, employment</p> <p>Strive to maintain normalcy</p> <p>Keeping family life as normal as possible</p>	<p>Provide a clear plan of action</p> <p>Anticipate and work to minimize the unpleasant side effects of treatment</p> <p>Exquisite management of physical symptoms</p> <p>Support the patient's optimism and perseverance</p> <p>Mental health professional for cognitive-behavioral coping skills</p>

Crisis Event	Cancer Survivor Responses	Survivor Goals	Oncologist Supporting Survivor
Remission	<ul style="list-style-type: none"> Relief Gratitude Dodged a bullet Hypervigilance over health Hypochondriacism Fear of recurrence Obsessive thoughts Loneliness Anger Exerting control Altruistic bargaining Search for meaning Fear Anxiety 	<ul style="list-style-type: none"> Rehabilitation- psychological and physical, cognitive difficulties, restoration of self-worth. Image recovery Managing emotions around fear of recurrence Refocusing in work and family life Redevelop intimacy 	<ul style="list-style-type: none"> Maintaining a scheduled set of follow up visits Exquisite management of physical symptoms Support psychosocial rehabilitation Provide emotional support Referral should be made to a peer support group, if requested If distressed, referral to mental health professional
Recurrence/new Primary	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Maximize a sense of personal control Maintain self-worth Skills to manage emotions Integrate reality of illness and family implications Control fear of death 	<ul style="list-style-type: none"> Delineating the next steps Exquisite management of physical symptoms Assure the patient will never feel abandoned Encourage a family meeting Physical ability Honesty, information, hope, and support Referral for supportive psychotherapy or cognitive-behavioral skills training

Crisis Event	Cancer Survivor Responses	Survivor Goals	Oncologist Supporting Survivor
Advancing Disease	Depression Anxiety Demoralization Fear Denial Anger Fear of intimacy	Dignity Direction in life Maintain role in work, family and community Manage guilt about being a burden Make a contribution Control fears of abandonment	Exquisite management of physical symptoms Request a family meeting Physical availability Redefine goals of treatment Encourage the search for meaning Honesty, information, hope, and support Reassure the patient and family that all that 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 Event	Cancer Survivor Responses	Survivor Goals	Oncologist Supporting Survivor
End of Life	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 To be surrounded by family Control fears of abandonment Manage guilt about being a burden Make 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 Reassure the family that all that could be done was in fact done

References

- ¹ Block, SD. Psychological considerations, growth, and transcendence at the end of life: The art of the possible. *JAMA*. 2001 Jun 13;285(22):2898-905. [PMID: 11401612](#). [Full Text](#).
- ² Coward, DD, Kahn, DL. Resolution of spiritual disequilibrium by women newly diagnosed with breast cancer. *Oncol Nurs Forum*. 2004 Mar-Apr;31(2):E24-31. [PMID: 15017451](#). [Full Text](#).
- ³ Bonanno GA, Papa A, O'Neill K. Loss and human resilience. *Applied & Preventive Psychology*. 2001;10(3):193-206. [Full Text](#).
- ⁴ Baltes PB, Staudinger UM, Lindenberger U. Lifespan psychology: Theory and application to intellectual functioning. *Annu Rev Psychol*. 1999;50:471-507. [PMID: 15012462](#). [Full Text](#).
- ⁵ Fleer J, Hoekstra HJ, Sleijfer DT, Hoekstra-Weebers JE. Quality of life of survivors of testicular germ cell cancer: a review of the literature. *Support Care Cancer*. 2004 Jul;12(7):476-86. [PMID: 15179563](#). [Full Text](#).
- ⁶ Bower JE, Ganz PA, Aziz N. Altered cortisol response to psychologic stress in breast cancer survivors with persistent fatigue. *Psychosom Med*. 2005 Mar-Apr;67(2):277-80. [PMID: 5784794](#). [Full Text](#).
- ⁷ Shimozuma K, Okamoto T, Katsumata N, et al. Systematic overview of quality of life studies for breast cancer. *Breast Cancer*. 2002;9(3):196-202. [PMID: 12185329](#).
- ⁸ Koopman C, Nouriani B, Erickson V, Anupindi R, Butler LD, Bachmann MH, Sephton SE, Spiegel D. Sleep disturbances in women with metastatic breast cancer. *Breast J*. 2002 Nov-Dec;8(6):362-70. [PMID: 12390359](#). [Full Text](#).
- ⁹ Sulmasy, DP. A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist*. 2002 Oct;42 Spec No 3:24-33. [PMID: 12415130](#). [Full Text](#).
- ¹⁰ Kutner JS, Steiner JF, Corbett KK, Jahnigen DW, Barton PL. Information needs in terminal illness. *Soc Sci Med*. 1999 May;48(10):1341-52. [PMID: 10369435](#). [Full Text](#).
- ¹¹ Breitbart W, Gibson C, Poppito SR, Berg A. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. *Can J Psychiatry*. 2004 Jun;49(6):366-72. [PMID: 15283531](#). [Full Text HTML](#). [Full Text PDF](#).
- ¹² Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med*. 2002 Feb;54(3):433-43. [PMID: 11824919](#). [Full Text](#).
- ¹³ Hodges LJ, Humphris GM, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc Sci Med*. 2005 Jan;60(1):1-12. [PMID: 15482862](#). [Full Text](#).
- ¹⁴ NCCN practice guidelines for the management of psychosocial distress. National Comprehensive Cancer Network. *Oncology (Williston Park)*. 1999 May;13(5A):113-47. [PMID: 10370925](#).
- ¹⁵ National Comprehensive Cancer Network (NCCN) Distress Management Practice Guideline. Jenkintown, PA: National Comprehensive Cancer Network, Inc., 2005. [Full Text Guideline 254 PDF](#).
- ¹⁶ Gupta MA, Gupta AK. Stressful major life events are associated with a higher frequency of cutaneous sensory symptoms: an empirical study of non-clinical subjects. *J Eur Acad Dermatol Venereol*. 2004 Sep;18(5):560-5. [PMID: 15324393](#). [Full Text](#).

- ¹⁷ Futterman A D, Wellisch Dk, Zigelboim J, Luna-Raines M, Weiner H. Psychological and immunological reactions of family members to patients undergoing bone marrow transplantation. *Psychosom Med.* 1996 Sep-Oct;58(5):472-80. [PMID: 8902898](#). [Abstract](#).
- ¹⁸ Bedell SE, Cadenhead K, Graboys TB, The Doctor's Letter of Condolence. *N Engl J Med.* 2001 Apr 12;344(15):1162-4. [PMID: 11302139](#). [Full Text](#).
- ¹⁹ Bryce CL, Loewenstein G, Arnold RM, Schooler J, Wax RS, Angus DC. Quality of death: assessing the importance placed on end-of-life treatment in the intensive-care unit. *Med Care.* 2004 May;42(5):423-31. [PMID: 15083102](#). [Full Text](#).
- ²⁰ Adapted from Loscalzo MJ, BrintzenhofeSzoc K. Brief crisis counseling. In: Holland JC, Breitbart W, Jacobsen PB, Lederberg MS, Loscalzo M, Massie MJ, McCorkle R eds. *Psycho-oncology*. New York, NY: Oxford University Press, 1998:662-675.
- ²¹ Cella D, Mahon S, Donovan MI. Psychosocial adjustment to recurrent cancer. *Oncol Nurs Forum.* 1990 May-Jun;17(3 Suppl):47-52. [PMID: 2342982](#).
- This descriptive study of semistructured interviews of people with recurrent malignancies addresses three questions: How do patients describe the meaning of a recurrence of cancer? Seventy-eight percent reported that recurrence was more upsetting than the initial diagnosis. This sample of patients experienced a lot of psychological distress as well as problems at home, work, and in their social lives.
- ²² Aldwin CM. *Stress, coping, and development: an integrative perspective*. New York, London: The Guilford Press; 1994.
- ²³ Yedidia MJ, MacGregor B. Confronting the prospect of dying: Reports of terminally ill patients. *J Pain Symptom Manage.* 2001 Oct;22(4):807-19. [PMID: 11576797](#). [Full Text](#).
- ²⁴ Richards TA, Folkman S. Response shift: A coping perspective. In *Adaptation to changing health: Response shift in quality-of-life research*. (pp. 25-36). Washington, DC, US: American Psychological Association, Washington, DC; 2000.
- ²⁵ Sullivan MD. Hope and hopelessness at the end of life. *Am J Geriatr Psychiatry.* 2003 Jul-Aug;11(4):393-405. [PMID: 12837668](#). [Full Text](#).
- ²⁶ Kaufman SR, Shim JK, Russ AJ. Revisiting the biomedicalization of aging: clinical trends and ethical challenges. *Gerontologist.* 2004 Dec;44(6):731-8. [PMID: 15611209](#). [Full Text](#).
- ²⁷ Vladimarsdottir U, Helgason AR, Furst CH, Adolfsson J, Steineck G. Long-term effects of widowhood after terminal cancer: a Swedish nationwide follow-up. *Scand J Public Health.* 2003;31(1):31-6. [PMID: 12623522](#). [Full Text](#).
- ²⁸ Kiecolt-Glaser JK, Preacher KJ, MacCallum RC, Atkinson C, Malarkey WB, Glaser R. Chronic stress and age-related increases in the proinflammatory cytokine IL-6. *Proc Natl Acad Sci U S A.* 2003 Jul 22;100(15):9090-5. [PMID: 12840146](#). [Full Text](#).
- ²⁹ Vitalian PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin.* 2003;129(6):946-972. [Full Text](#).