Chapter 13
Building a Critical Mass of Health-Care Providers, Administrators, and Services for Cancer Survivors

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Introduction

To build a critical mass of health-care providers, administrators, and services for cancer survivors, education about cancer survivorship and multidiscipline involvement in survivorship care activities is the initial and essential step. One cannot practice what one does not know. This education is most successful when developed by those with educational expertise. This chapter focuses on the initial definitions needed to begin an educational program in cancer survivorship care, approaches to define the content or curriculum needed, approaches to conducting educational needs assessments, how to formulate educational objectives, how to identify appropriate teaching methods, and will end with approaches to evaluations. Examples focused on cancer survivorship care are provided throughout.

Innovative educational efforts in survivorship care are beginning to emerge as a National Action Plan for Cancer Survivorship was identified along with the recommended content of a survivorship program (Table 13.1) [1]. Providing survivorship care in general requires an understanding of the overall picture of survivorship care and how this content applies to each discipline involved in this care. Curriculum has been developed to help medical schools and nursing schools improve the understanding of cancer survivorship for health-care professionals and anticipate their health needs for their future (Table 13.2). The Institute of Medicine (IOM) report on Cancer Survivorship (2006) defined the components of survivorship care. This report also included raising awareness of the needs of cancer survivors and recognizing that surviving cancer will change the patients' future health-care concerns and will affect their families and caregivers as well.

The definition of a cancer survivor varies across organizations, institutions, and settings. Survivorship according to the IOM report begins at the time of diagnosis and beyond and includes the family and caregivers. Other programs may refer to cancer survivors as patients who have completed cancer treatment, and still others

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Table 13.1 A National Action Plan for Cancer Survivorship: Public health strategies (Adapted from IOM Box 4-7 Communication, education, and training, p. 246; [1])

Administrators	Health professionals	Patients	Public	Components
Overview of survivorship care (SC) Develop, test, maintain, and promote patient navigation systems for people living with cancer	Overview of SC. Educate HCP about issues from diagnosis through long-term treatment effects and end-of-life care	Empower with advocacy skills	Strategies to educate that cancer can be a chronic disease. People do survive	Physical
Educate policy and decision makers about the role and value of long-term follow-up care Improved quality of life Patient and staff satisfaction	Educate policy and decision makers about the role and value of long-term follow-up care Quality-of-life issues Legal needs Access to clinical trials Multidiscipline resources	Teach survivors how to access and evaluate available information Multidiscipline management – referrals to psychosocial support programs, Occupational Rehabilitation/Physical therapy, Treatment Summary/ Survivorship Care Plan	Positive attitudes toward health maintenance and early diagnosis	Psychosocial
QoL	QoL	QoL, spiritual support	QoL	Spiritual
Legal needs	Legal needs	Legal needs	Accountability for health care	Coordination
Access to clinical trials, positive PR	Access to clinical trials. Positive PR Survival & pt. satisfaction	Positive outcomes – patient satisfaction and improved survival	Access to clinical trials. Positive outcomes – Health Promotion	Media/marketing Public forums

Table 13.2 Professional education programs in cancer survivorship

American Society of Clinical Oncology (ASCO)	Education and training – survivorship focused programs	http://www.asco.org
Office of Cancer Survivorship	Educational tools and resources for patients and families	http://survivorship.cancer.gov
American Academy of Family Physicians	Educational programs related to adult survivors of childhood cancers and general education about cancer risk and improved outcomes	http://search.aafp.org
American Cancer Society	Educational resources for survivors after treatment	http://www.cancer.org
CancerCare	Resources to help health-care professionals stay informed of current cancer practice and issues in psychosocial oncology	http://www.cancercare.org/professionals/progressional_ed.php
Nurse Oncology Education Program (NOEP)	CNE programs for nurses in survivorship care	http://www.noeptexas.org/
Oncology Nursing Society	Clinical practice resources and CNE offerings	http://www.ons.org/clinicalresources

may define it related to the number of years posttreatment, that is, 5 years posttreatment. One of the first steps in developing a survivorship education program is to decide on a definition of survivorship and address professional and patients' needs related to that setting.

The deficits in education of survivors as well as health-care providers are related to a number of factors. Barriers to providing survivorship education include staffing and financial concerns effecting health-care systems in general today. Growing concerns about deficits in the future oncology workforce of physicians and nurses add to the challenge of providing patient and family education. Health-care providers must be aware of outside services and resources available for survivors and their families. A multidiscipline as well as multisystem approach will provide the most efficient methods for meeting the IOM recommendations for cancer survivorship care.

The IOM components of cancer survivorship care include the following parts: prevention/detection and surveillance, interventions, and coordination (Fig. 13.1). Defining educational activities within those components will be the focus of this chapter.

Prevention/Detection

Prevention and detection are two very important areas for future education and research. This survivorship program component is defined as "prevention of recurrent and new cancers, and of other late effects." Promoting healthy lifestyles is

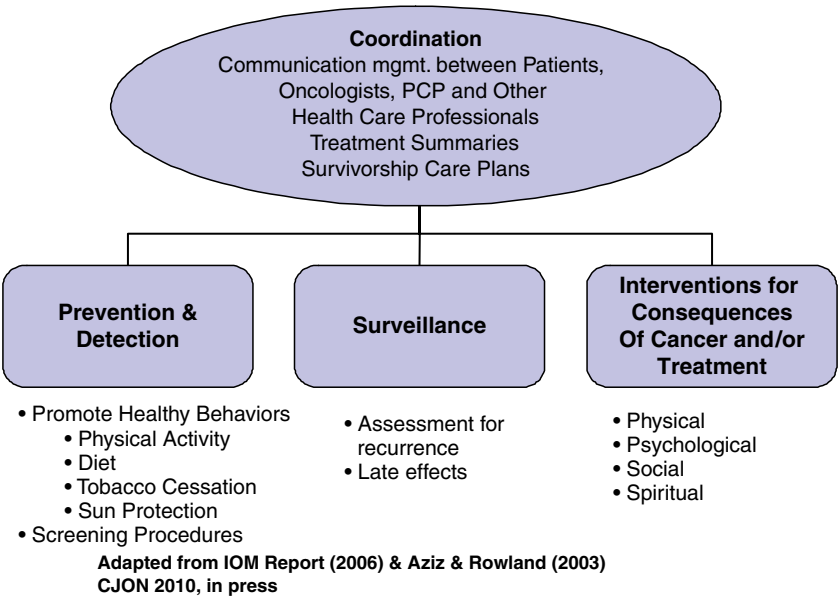

Fig. 13.1 IOM components of survivorship care

important here and includes techniques that can prevent new cancers and reduce the risk of recurrence. Tobacco cessation is an excellent example of health promotion activities. Educating to provide this type of activity is most difficult because it involves changing behaviors. Changing behaviors involve changing an attitude toward these activities and even with education, improved knowledge does not always lead to behavior changes. In order to meet those challenges as health-care providers, the first step is to understand the attitudinal barriers to these activities and develop educational strategies toward changing those attitudes to promote changes in behavior [2].

Education about this component begins by understanding the population being served. Needs assessment can help gather facts regarding health promotion, smoking, and obesity attitudes. A questionnaire for patients, families, and caregivers can identify barriers to these activities and provide information needed to develop appropriate objectives for the instructional plan. Guidelines for prevention and detection strategies can be found through the American Cancer Society [3] and the National Comprehensive Cancer Network [4]. Once the objectives are identified then the lesson plan can be developed and the teaching methods to be used defined.

An example of a primary prevention program is an ongoing education program for adolescents and young adult cancer survivors on health, wellness, and cancer prevention. Within that program, attitudes toward health behaviors can be identified and promotional strategies incorporated into the education. Providing factual information along with motivational activities and modeling of these behaviors over the length of the course can lead to behavioral changes. Offering follow-up support and booster sessions through written references or electronic access to

health professionals can improve outcomes. Behavioral change requires multiple methods to reinforce the desired outcomes. Combining the educational piece, with evidenced-based data on health promotion benefits, and providing guidelines for quality improvement activities to document changes in behavior round out a successful educational plan [5].

Surveillance

Surveillance as a component of survivorship care involves observing for cancer spread, recurrence, or second cancers. It also includes assessment of medical and psychosocial late effects. Adult survivor guidelines for surveillance remain consensus focused using current evidenced-based studies as appropriate. Recommendations for surveillance postcancer treatment include American Society of Clinical Oncology (ASCO) and the National Coalition of Cancer Network (NCCN). The American Cancer Society (ACS) has been a keystone to teaching the general public on cancer risk and symptoms associated with cancer development. Examples of surveillance programs for cancer survivors may include implementing psychosocial screening for symptoms of distress and depression into follow-up practice; establishing adult surveillance and education programs for survivors of childhood leukemia; developing a resource program for patients and families recently completing treatment which includes information for surveillance follow-up care and testing, general treatment effects, and symptoms to be reported to the physician.

Interventions

Interventions within survivorship care are focused on providing support for the consequences of cancer and its treatment related to patients and caregivers and supporting quality of life. Using the quality-of-life model related to cancer survivors [6], education can be organized around the four domains. Physical consequences of cancer and its treatment include programs developed around symptom management strategies. Programs related to lymphedema management, skin care, fatigue and pain management, as well as healthy lifestyle education and sexuality and fertility programs are examples of survivorship care needs that can be addressed in these programs. Psychological needs programs can be built around coping, stress management, and family and caregiver support programs. Social issues include issues related to employment, insurance, and disability. Spiritual support programs would include general spiritual guidance or ways to promote resilience, and restorative activities that provide an environment and guidance to deal with existential feelings or religious focused support. Interventions are developed around needs assessments to identify areas of concern within a specific population, late and long-term effects education, health promotion activities, and survivorship celebration days to provide educational events for patients and families.

Coordination

Coordination of care among patients, specialists, and primary care providers to guarantee that survivors' needs are met is essential to the success of survivors' follow-up care. This requires multiple disciplines to work together from the health-care providers to the information technologists in a joint effort to retrieve necessary information, document it, and provide it to the patient and their health-care team. Treatment Summaries (TS) and Survivorship Care Plans (SCPs) fall into this category and have been recommended by the Joint Commission, IOM and the American Society of Clinical Oncology and European Society for Medical Oncology (ASCO-ESMO) for the promotion of quality cancer care [7]. These tools would serve to assess and support uncontrolled side effects, provide for early detection of recurrence or new cancers, and avert preventable consequences such as osteoporosis and heart failure. They provide the framework of communication for all educational activities.

Although this component of survivorship care has become a major challenge due to multiple medical records, multiple treatment sites, and the inability for electronic medical records to link with other electronic documentation programs, strides are being made. Online documentation programs available to everyone have allowed patients to access these tools and begin building their own personal TS and care planning tools. Providers who have limited staff to provide these tools within their practice can be most helpful by educating and supporting their survivors in accessing and completing these tools on their own. Examples of activities being done in this area include providing all newly diagnosed cancer patients with a treatment summary template to begin documenting their treatments starting at diagnosis. Educational classes or instruction sheets can be provided to new patients to assist them with gathering these data [8, 9].

Assessing the Needs of Specific Education Audiences

Needs assessments are used to gather information about patients, providers, or settings. Assessments may include patients and caregivers but also administrators, health-care professionals, and public consumers. This information helps identify deficits or needs in care, education, or systems, and helps define how best to use resources. Needs assessments are used to plan education or interventions to meet the identified needs. They provide the what, how, and why of program planning. Multiple tools are available and electronic programs such as SURVEY MONKEY can be very helpful for developing a questionnaire that can be provided electronically and will coordinate the results to make using the information easy [10]. Assessment questions may be general to allow short answers and provide the educator with overall information on the population and the interests or concerns they have. Needs assessment tools can target specific areas such as healthy behavior

education focused on lifestyles, diet, financial concerns, or health screenings and smoking cessation. Tools may be used as a learner self-assessment to rank the degree of competence staff may have for providing certain skills or interventions. Needs assessments are the first step in planning education that will be relevant to the population being served. Collecting needs assessments from a variety of survivorship populations can be done in different settings. Formal or informal meetings can be used to gather this information. Patients and caregivers can complete needs assessment tools during patient visits, be directed to hospital web sites, or during cancer patient events like a yearly survivorship celebrations. Satisfaction surveys can include open-ended questions regarding patients' wishes or requests that would provide assessment information as well. Examples of needs assessment tools can be found at the Pain & Palliative Care Resource Center, City of Hope (http://www.prc.coh.org). Needs assessments can be important tools for evaluating the knowledge level that administrators or health-care professionals have regarding survivorship care in an institution or setting. Without administrative support for survivorship care, efforts may be stunted or abandoned. Participating in committee meetings where administrators are attending is an important part of program building. Presenting the survivorship care–planned interventions is important, but must begin with the buy-in of the administrator.

Using survivorship care interventions including patient interviews or video programs, such as the IOM Cancer Survivorship video, helps non-health-care providers hear what patients are saying in their own voice. Recruiting support from administrators with experience in cancer either personally or from a family member or friend's knowledge can build understanding in the program's goals from a cognitive or emotional understanding. Assessing these populations is essential to build value for survivorship care and to bring them from casual acceptance to true commitment for the program. Defining the target audience for education is essential. Administrators, health-care professionals, patients, and public require different strategies. Administrators may be interested in physician satisfaction or systems satisfaction as in documentation systems or patient scheduling systems. They are generally interested in satisfaction results and cost-effectiveness of these programs. Health-care professionals need specific medically focused information to meet their needs. Using online educational programs or in-service type programs can provide detailed in-depth information for professionals. Patients need similar medical information that may be individualized but tempered with less detail. Public education is broader and provides more general information. Resources like the ACS, Cancer Care, and the Lance Armstrong Foundation have developed educational materials specifically for the public including caregivers and family focused information.

Additional information to consider when planning a program would include the information gained from the needs assessments as well as considering what the education program has to offer. Can you provide a new perspective for addressing the identified needs? Can you provide concrete answers to the problems or share information from a national perspective to help build new skills or assure the participants that they are providing the level of care needed?

Developing Learning Objectives Related to Those Needs

Learning objectives define what the educator anticipates that the learner will gain from the activity. They communicate the educators' intent for the participants and provide details to help build the lesson plan. Based on Bloom's Taxonomy of Learning Domains, there are three types of learning: cognitive or knowledge building, affective or attitude growth, and psychomotor or skill building [2]. Learning objectives are developed to provide the specific actions necessary to promote learning in the subject [11].

Cognitive or knowledge-focused objectives provide facts about a specific subject. Objectives could include providing information to improve knowledge or providing new facts regarding a subject. An example of a knowledge objective would be to learn three disease-specific long-term or late effects related to breast cancer treatment. Teaching methods for this type of objective would not only include lecture or didactic format but also include web-based learning modules with posttest evaluations to verify the extent of knowledge improvement. Learning games and handouts to reinforce facts are very helpful.

Attitude objectives are meant to increase positive feelings or emotions around an area or to reinforce or provide new insights into the value placed on a concept by an organization or group. In survivorship, building the case for survivorship care and the phenomena of awareness of the needs associated with cancer survivorship and the long-term and late effects of treatment are essential to growing these programs. The IOM's 2006 report provided a video of patients discussing their needs, which elicits an emotional response in providers and patients who view this video [12]. The awareness of survivors' needs is made very visual. Objectives aimed at raising awareness and emphasizing values and behaviors that meet the organization's goals are attitudinal. An example of an attitude objective would be to assess personal feelings associated with providing survivorship information to your patients. Methods used to carry out this objective might include a general overview lecture, a Lunch & Learn, or a case study to help encourage a discussion about fears or knowledge deficits that may be hindering the action of providing survivorship information to patients. Opening up discussions and providing information regarding survivors' needs are essential and provide the basis for building a philosophy within an institution or setting.

Psychomotor objectives are aimed at improving specific skills. They are used to train staff in new techniques or procedures and are easily measured. An example of a psychomotor objective might be to demonstrate how to complete an SCP. Components of an SCP would be identified and a template might be provided or recommended. Small groups work well for achievement of these objectives. Posttesting, role play, or return demonstrations are important assessment features of psychomotor objectives. Examples of objectives are found in Table 13.3.

Table 13.3 Objective examples in survivorship care

Objective type	Sample objective
Attitude objectives – feelings, emotions, and values	Recognize the need for survivorship follow-up care for cancer patients
Knowledge objectives – facts, improved knowledge	Describe the survivorship programs available to patients and how to refer to those programs
Psychomotor objectives – improve skills	Conduct a survivorship follow-up visit and provide a treatment summary to the patient

Educational Methods

Many different and creative methods can be used to provide survivorship education to different populations. Based on the types of objectives set for a program, teaching methods can follow. For example, standard programs like lectures, live face-to-face, grand rounds, or Lunch & Learns are best when trying to convey general knowledge building principles or an overview of survivorship care. These provide factual information. Case study and self-study programs can also be effective. Providing these programs as web-based or online access may also improve participation. Health-care providers face many challenges for time; allowing access from home computers and flexibility of timing can help them access these educational programs. The amount of research data published today continues to be underused in practice. Connecting the information to the people who would benefit from it is difficult. For example, using electronic prompts can be useful in encouraging health promotion activities or prompting physicians on how often to order surveillance tests. One study found that using prompts called "provider reminders" to physicians increased preventive care activities by 13.1% [13]. Depending on your audience you would choose the appropriate providers or venue to convey the information. Using professional speakers is a recommended approach when attempting to deliver general information to physicians. Health-care professionals look for data associated with the information and are more likely to accept recommendations when they are presented from a scientific perspective. Administrators and patients benefit from that type of speaker as well but will also appreciate the personal perspective that a survivor or professional providing that care may share.

Attitude objectives require different approaches to reach successful results. Attitude objectives are focused on feelings or values and need time to be discussed, and reframed if necessary. Providing provocative questions to understand how someone may feel about the subject and sharing attitudes in small group discussions may be necessary. From an administrative or health-care provider standpoint, these changes in philosophy may have a significant impact in the daily provision of patient care. Modeling the benefit of survivorship care and the improvement in quality of life for these patients is important and is a crucial part of the process to allow for a transition in the type of care provided.

Psychomotor or skill-focused objectives require methods of instruction that require physical activity and written instructions. Methods include written guidelines, demonstration models, and return performance opportunities. Time must be provided to practice these new skills in a nonjudgmental environment. Examples in survivorship care activities might be teaching lymphedema massage or symptom assessment skills. This method requires an active learner and provides for learning new skills.

Survivorship days and large multiday education programs can be used to meet multiple needs for cancer survivors, health-care providers, and caregivers. In many settings, an annual recognition day for cancer survivors is provided. It allows for a positive celebration of survivorship for cancer survivors, families, and caregivers, and is an opportunity for community involvement and sharing resources with other cancer support services like the ACS, LIVESTRONG, and CancerCare to take place (http://www.cancercare.org). Institutions have partnered with community resources that provide psychosocial support, physical therapy, and nutritional services in their community to share the cost but also reach a greater number of participants. This is also a great venue for collecting needs assessments from the participants. These are usually programs that attract large numbers of cancer survivors, their families, and caregivers. They can be an excellent way to kick off a plan to provide survivorship care in a setting and gather the information needed to steer the educative components of a program in an appropriate way. Examples of programs to meet the essential content of survivorship training for health-care providers can be found in Table 13.4.

Table 13.4 Survivorship training content and recommended programs (Adapted from IOM report Box 5-1 p. 327; [14])

Essential content of survivorship training for health care providers	Recommended programs
Prevention of secondary cancers	Health promotion activities – smoking cessation, skin examinations, nutrition, and exercise recommendations
General discussion of survivorship	Survivorship day programs, support group formats, Lunch & Learn, grand rounds
Long-term/late effects of cancer and its treatment	Lymphedema, cardiac complications, psychosocial issues
Health-care systems/quality assurance/models of care	Patient and health-care professionals needs assessments. Overview of models of care, research, or clinical focused care
Rehabilitation services/ occupational therapy	Available programs and services offered within your setting or community
Quality-of-life issues in survivorship	Focus on improved quality of life within a setting or disease focus. Psychosocial support, occupational needs, and sexual issues
Detection of recurrent and secondary cancers	Surveillance programs – educate primary care physicians on detection and surveillance recommendations
Pain management	Educate health-care providers on managing pain. Provide access for patients to pain management programs
Palliative care/end-of-life care	Aggressive symptom management, access to palliative and hospice care as needed
Short-term complications	Acute symptom management clinics
Treatment of recurrent cancer	Easy referral back to oncologist and oncology program

Multiday educational programs have been used to provide an educational curriculum to health-care providers or survivors. The curriculum is built to meet the needs of a particular population and may be related to general education for patients and families or to train health-care professionals in specifics of survivorship care. Survivorship Education for Quality Cancer Care was one of the first multidiscipline training programs funded by the NCI. The curriculum was developed with expert faculty input around the time the IOM report was published. Sessions defining the physical, psychological, social, and spiritual effects of cancer survivorship provided a guideline for program planning. Over the course of 5 years, four training programs were completed and 104 teams from cancer settings across the nation attended [15]. Goal analysis was used to evaluate the success of the training program. Data collected showed that participating institutions improved survivorship care in their settings. Evaluation of educational programs is necessary to justify the financial and time commitment of a program. Dissemination of information is essential but evaluating the extent that the training met its goal and provided the proposed information must come first.

Evaluating Programs

Evaluation of training programs provides data that affirms the information taught was received as intended. Financial support of the program either from institutional support or NCI funding requires evaluation data. A formative evaluation focuses on the process of the educational program. It is an opportunity to evaluate the learning materials and teacher effectiveness as well as achievements throughout the development and application of the program. Summative evaluation evaluates a program at the end, so focuses on the outcome [16]. Evaluating training programs have been historically measured for effectiveness using the Kirkpatrick model [17]. It is useful because it uses four levels for evaluating effectiveness of the program based on different goals of the evaluation. The first level, reaction, is used most often. This is a basic evaluation of satisfaction with the program. Simple evaluation tools ask if the program met the program's objectives. The next level evaluates the extent to which the participants increased their knowledge or changed their attitudes. These would be measurable evaluations with scales rating the increase or change in attitude or knowledge. The next level, behavior evaluations, requires a more interactive evaluation. This level of evaluation measures the extent to which behavior has changed. These are usually done by supervisors or observers who either through interviews, chart audits, or direct observation can measure a change in behavior. For example, after providing an educational session, nurses are documenting patient education that includes survivorship care. Finally, the fourth level of evaluation is called results. Results evaluations determine the final results of training. They are similar to behavior evaluations by including a measurement of a changed behavior but go beyond that to include a philosophical change in attitude and practice. An example of results, evaluations in the Survivorship Education for Quality Cancer Care program described above involved a required Institutional Assessment that identified

system areas that changed from baseline to 18 months post course. In this case, there were significant differences in the seven domains that included vision and management standards, practice standards, psychosocial and emotional standards, communication standards, quality improvement standards, patient and family education post cancer treatment, and community network and partnership standards [18]. Evaluations are necessary not only to help define the quality of a new program or the faculty providing it but also to justify the cost of the program either personally, administratively, or institutionally. The future of health care will be much more focused on outcomes data and tied to reimbursement. Changes in government monitoring and oversight are expected. Professional societies have been involved in evaluation of programs and patient care for quality. The Quality Oncology Practice Initiative (QOPI) is a project by the ASCO to collect data about the quality of care provided to patients in an effort to standardize care and establish indicators that compare performance [19]. Keeping track of the benefits of programs provided as they relate to the patient, the provider and the family will be essential for the future.

The recommendations for quality cancer care include survivorship care planning as part of the long-term follow-up plan for cancer patients [7]. Access to information as well as prevention services and pain and palliative care are included. How we provide this information is a challenge. Multidiscipline collaboration for providing education and resources to patients, health-care providers, families, and caregivers is essential. Multiple venues and methods of education require experts in additional areas beyond the physical components and development of survivorship education programs or materials. Information technologists, web masters, and template experts all contribute to the dissemination of survivorship knowledge. Creative methods reviewed have found that using venues appropriate to age-specific survivors can be effective. Participating programs have discussed using rooms associated with coffee houses, for instance, to meet young adults. They are off site and provide a low key area to meet and discuss issues affecting their lives. Another site that provides access to families and caregivers and provides an area to post general educational information or provide specific marketing information for a particular program is the local mall. Centers have been able to use empty storefront windows to post information and calendars of events for cancer survivors in their community. Hospitals have found those to be very cost effective and positive outcome expenditures for marketing dollars along with providing excellent public relations information. As people walk through the mall, they can read information on cancer prevention and detection, pick up information, or attend educational programs. Table 13.5 provides examples of additional education techniques.

Future

An important part of survivorship education is helping patients build self-advocacy skills. Developing programs to help survivors learn skills to manage the many and ever-changing informational needs they experience is essential [20]. Innovative educational efforts for cancer survivorship care involve didactic and interactive

Table 13.5 Educating objectives and related teaching methods

Type of objectives	Teaching methods
Attitude – Feelings, attitudes, and values	Lectures Grand rounds Lunch & Learn Web-based learning modules Videos Discussions-small group Knowledge and attitude testing Role play modeling Case studies List values – prioritize/contrast different values, compare, and synthesize Listening exercises
Knowledge – providing facts and information	Handouts Posters Lectures Web-based learning modules Videos Games Pre- and posttesting
Psychomotor – techniques or procedures	Lecture – small groups with posttest or return method evaluation Modeling new procedure-role play Web-based learning modules with posttest or return evaluation Handouts describing technique or procedure

programs along with media, online resources, and coordination of these efforts. Assessing the needs of the setting and developing appropriate activities aimed at motivating the participants, and providing the information needed is essential for providing successful educational programs. As survivorship care continues to be recognized as an essential part of quality cancer care, educating health-care professionals and support staff will be a necessary aspect of providing quality health care.

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