Maximizing Benefits for Effective Cancer Survivorship Programming: Defining a Dissemination and Implementation Plan

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LEARNING OBJECTIVES

After completing this course, the reader will be able to:

1. Outline a process that cancer organizations can use to design, implement, prioritize, and evaluate cancer survivor programs.
2. Describe the scientific evidence for benefit from survivorship interventions and the process and strategies for implementation and evaluation to promote sustainable programs.

This article is available for continuing medical education credit at CME.TheOncologist.com.

ABSTRACT

Although calls for improvements in cancer survivorship planning and programming exist, implementation has lagged. As with most guidelines, moving from recommendations to implementation requires active planning and systems changes to insure sustained use. Here, we draw on the latest in implementation science to outline a process that cancer organizations can use

in designing, implementing, prioritizing, and evaluating cancer survivor programs to improve patient outcomes, using smoking cessation as a primary example. We consider the scientific evidence for benefit from interventions and the strategy for implementation and evaluation to sustain programs. *The Oncologist* 2011;16:1189–1196

THE CHALLENGE

The need for cancer survivor care planning was addressed extensively in the 2007 Institute of Medicine (IOM) Imple-

menting Cancer Survivorship Care Planning report [1]. This report focused on the creation of patient care plans. Since then, additional care plan tools have become avail-

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able (such as Journey Forward [2]), yet insurance coverage for the development and implementation of these plans remains sparse [3]. Despite efforts to develop professional education courses in cancer survivorship [4], few cancer centers have systematically implemented patient care plans as outlined. With >12 million cancer survivors in the U.S. today [5], there is great need for survivor programs. Moreover, given that these survivors receive care from a wide spectrum of organizations (from comprehensive cancer centers to community cancer centers and group practices), the organizational resources available to implement and sustain programs for cancer survivors vary substantially. Although the IOM survivorship report documented the features that might be included in a survivorship program and the supporting evidence behind such offerings, the process of deciding which programs to offer remains unaddressed, as does the challenge of implementing them. As noted by Oeffinger and McCabe, survivor care does not generally extend beyond surveillance or occasional specialized services [6]. As with most guidelines, moving from recommendations to implementation requires active planning and systems changes to insure sustained use [7]. Given the limited resources available, prioritizing survivorship programming in a systematic way is imperative, particularly given that some of the largest projected costs of cancer care are expected in the continuing phase of care [8]. Although several models for comprehensive survivorship programs have been outlined [6], comparatively little attention has been devoted to *how* those programs get implemented.

In this review, we outline a process that clinics, hospitals, and cancer centers can use in designing, implementing, prioritizing, and evaluating cancer survivor programs to improve outcomes for patients in a way that maximizes benefits. We provide a framework to help organization leaders choose which program to offer and describe a model for implementing the chosen programs. The IOM report focuses on outcomes defined as “service outcomes” by Proctor et al. [9], separate from the implementation outcomes that characterize intervention science. Implementation of survivorship programs will include all three aspects of implementation outcomes outlined by Proctor et al. [9]—implementation, service, and client. These outcomes are in line with the consolidated framework for implementation research, which comprises five domains: intervention characteristics, outer setting, inner setting, individual characteristics, and the implementation process [10]. Our primary focus here is the implementation process from selecting the program to evaluating its implementation. We focus on the process of identifying and implementing programs for organizations engaged in the initial care and subsequent follow-up of survivors.

Implementing Programs in a Cancer Survivorship Setting

Figure 1. Implementing programs in a cancer survivorship setting.

Applying the latest approaches from implementation science, we outline a process that cancer organizations can use in designing, implementing, prioritizing, and evaluating cancer survivor programs to improve patient outcomes. We consider the scientific evidence for benefit from interventions and the strategy for implementation and evaluation to sustain programs.

SOLUTIONS

Cancer centers and oncology practices typically offer a range of educational and support programs for patients, families, and survivors. The range of topics covered in these programs is immense and typically has overlap with the American Society of Clinical Oncology (ASCO) rehabilitation areas [11]. The implied goal of these programs is an improvement in quality of life (broadly defined), but many have not been evaluated. In addition to programs offered at physical hospital centers, other organizations also address survivor programming. For example, ASCO’s patient-centered Web site [12] references a number of potential rehabilitation programs and partners for survivors [11]. However, the Web site offers no guidance on which programs are mostly likely to offer benefit or what benefits might be derived from a given program. Likewise, in the cancer site-specific area, Susan G. Komen for the Cure offers Web resources [13] but does not link individual patients to specific activities. Some programs focused on specific content areas, such as pain management [14] and end-of-life care [15], have been evaluated and disseminated but lack widespread evaluation of implementation across institutions. Finally, several institutions are working to implement models of survivorship care through the Live-strong Survivorship Center of Excellence Network [16].

Here we propose a process (Fig. 1) by which organiza-

Table 1. Smoking cessation for cancer survivors: applying components of the implementation cycle

1. Stakeholders: Convene survivors undergoing treatment and post-treatment, caretakers, clinic administrative staff, nurses, medical oncologists, surgeons, and radiation oncologists.
2. Goals: Reduce mortality from smoking-related disease among cancer patients and survivors. Reduce exposure of patients, families, and staff to secondhand smoke. Reduce smoking rate among cancer patients, particularly those with high rates of smoking (e.g., head and neck cancers).
3. Program options: <ul style="list-style-type: none"> a. Smoking cessation program in hospital b. Promoting and referring to external cessation programs c. Enforcing smoke-free rules in and around hospital grounds d. Increase advertising and awareness for smoking cessation programs, targeting key areas including hospital entrances, places where smokers congregate on and off hospital grounds, and certain treatment clinics (e.g., head and neck cancer) e. Provide resources for smokers/quitters <ul style="list-style-type: none"> i. value of smoke-free home and work ii. local smoke-free bars and restaurants iii. community-level resources to support behavior change <p>Factors to consider: location for classes, cost (if any) of classes</p>
4. Metrics: <ul style="list-style-type: none"> a. Attendance at cessation classes (possibly broken down by patient, staff, caregiver) b. Smoking rates measured via self-report in patients (overall and in specific target groups) c. Mortality rate in head and neck cancer patients
5. Implement: <ul style="list-style-type: none"> a. Effectiveness of cessation class: high b. Acceptability of classes to stakeholders: high c. Sustainability: medium <p>Applying the Proctor equation using data from Emmons et al. (2005) [21]</p> $= f \text{ of } effectiveness + acceptability + sustainability$ <p>Implementation success = effectiveness (6% difference in 12-month quit rate between counseling and self help in Emmons et al. [21]) + acceptability (83% of eligible individuals enrolled in Emmons study) + sustainability (\$300 per participant, cost-effectiveness estimate is \$5,371 per additional quit as compared with \$7,000 per case for physician counseling plus nicotine replacement therapy)</p>
6. Evaluate <ul style="list-style-type: none"> a. Process—participation by stakeholders b. Outcomes (e.g., smoking prevalence, attendance overall and by cancer site, physician referrals)

tions can implement and evaluate survivorship programs. The figure indicates that this process is an ongoing and continuous one of evaluation and input. We use a smoking cessation program as a primary illustrative example (Table 1) and offer other examples as contrasts throughout.

Identify Stakeholders

The first step is to identify the stakeholders involved. Successful implementation depends largely on the program's fit with the preferences and priorities of those who shape, deliver, and participate in care. In cancer survivorship, this likely includes, but is not limited to, physicians, nurses, clinical staff, researchers, administrators, patients, and

families. At large cancer centers, the list of clinical care teams involved is vast and likely includes individuals from nearly every department or division. It might also include spiritual care, genetic counseling, palliative care, physical therapy, occupational therapy, social work, psychiatry, and psychology. Regardless of the breadth of disciplines and perspectives, input from stakeholders on each of the following steps is essential to build and sustain support for survivor programs [17]. Those convening the process will want to recognize that the financial constraints identified as a barrier to successful implementation of survivorship programming [4] include the extensive staff time needed to succeed. Research indi-

Table 2. Behaviors, program options, and outcomes to consider in survivorship program planning

Behavior	Outcomes	Example program	Benefits, risks
Smoking [35]	↑ recurrence ↑ mortality ↑ coronary heart disease ↑ stroke ↓ quality of life	Smoking cessation class	High failure rate, benefits reach across disease endpoints, immediate benefits
Obesity [36–38]	↑ recurrence ↑ mortality ↑ heart disease ↑ stroke ↑ diabetes	Weight loss	High failure rate, high cost associated with evidence-based programs
Exercise [22, 27, 37, 39]	↓ recurrence ↓ mortality ↓ heart disease ↓ diabetes ↓ stroke ↑ quality of life ↓ fatigue ↓ obesity	Walking	Immediate benefit, improvement in quality of life, minimal resource investment
Diet/nutrition [22, 37, 38]	↑ diet choices associated with weight loss	Nutrition counseling	Benefit of specific diet components unclear, but benefits for overall programs can be drawn from related fields (e.g., Diabetes Prevention Trial [40]).

cates that obtaining buy-in from all stakeholder groups is believed to be an important facilitator of the process [4].

Articulate Goals and Outcomes

The next step is to identify the goal or possible outcomes desired. Multiple outcomes may be included and vary across subgroups within a service setting. Typically, hospital programming goals focus on service and client outcomes only. Examples include improving patient satisfaction, improving quality of life in patients and caretakers, and improving rates of return for follow-up care—with higher compliance with treatment guidelines and a reduction in patient symptoms and side effects. Goals might also include improving overall or disease-free survival rates, though evaluation of such a goal also requires articulating a time frame for achievement. Other considerations may also be important, such as attendance and the need to provide programming for certain age or disease groups. This likely varies widely depending on the practice environment (e.g., a comprehensive cancer center versus a small group oncology practice). In our smoking cessation example, the hospital may be interested in reducing smoking rates overall, but also particularly among head and neck cancer patients,

among whom the prevalence of smoking is high [18, 19]. Implementation goals might include achieving high levels of adoption by providers, measured by referrals to the smoking cessation class.

Program Options

After desired outcomes are articulated, potential evidence-based programs that can address the desired goals must be identified. Institutions are encouraged to consider programs that may exist already, locally or regionally, to avoid duplication of effort and resources. Some possible approaches to identifying evidence-based programs are discussed below. In our smoking example, smoking cessation programs may be available within an affiliated hospital or a statewide quitline, or referrals may be made to a national resource such as “BecomeAnEX.org” [20]. Examples for other health behaviors might include community center exercise programs such as Livestrong at the YMCA or immunization programs such as flu shot clinics. It is important to recognize that the “lack of knowledge related to survivorship needs and care” was identified as the most frequent barrier to implementing survivorship activities in a recent study [4].

When choosing among program options, a key input

should be the established level of evidence for the effectiveness of a program. In many cases, reviews of risk factors for adverse outcomes in cancer survivors have been conducted, including that by Jones and Demark-Wahnefried in the 2007 IOM report [1]. (For a brief review of behaviors, outcomes, and other factors to consider, see Table 2). As noted in the report, with tobacco use causing nearly one third of cancers, the prevalence of smoking in cancer survivors remains a significant concern. However, smoking cessation is one of the areas in which high-quality, randomized, controlled trials of interventions have demonstrated success. For example, Emmons et al. [21] found significantly higher quit rates among adult survivors of childhood cancers randomized to a peer telephone counseling intervention with tailored print materials than among those randomized to standard self-help materials.

Stakeholders will want to decide what strength of evidence is needed for a program to be considered and under what circumstances a program might be included without evidence or extrapolated to other diseases or tumor sites. For example, lifestyle intervention trials have typically not restricted patient populations by tumor subtype, assuming results applied across subtypes or could reasonably be extrapolated. However, Pekmezi and Demark-Wahnefried recently suggested that evidence for the benefits of diet or exercise may be required from randomized trials of different tumor subtypes, putting a much greater burden on the evidence base [22]. Multiple options for programming evaluation and metric identification exist and institutions need to identify those that work for them, including the U.S. Preventive Services Task Force (USPSTF) [23] and the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system [24]. The USPSTF and GRADE give the highest recommendation to evidence from randomized, controlled trials in which the evidence indicates a likely net benefit, meaning that there is a high certainty of a substantial net benefit or moderate certainty that the net benefit is moderate to substantial. However, some programs with a moderate certainty of benefit may be recommended under the USPSTF guidelines if other considerations support it. Programs achieve a high level of certainty if there are “consistent results from well-designed, well-conducted studies in representative or similar populations which assess the effects of the service on health outcomes. As a result, future studies are unlikely to change the conclusion.” However, the body of research on lifestyle interventions in cancer survivors is small relative to the evidence for prevention of cancer and other chronic diseases, and institutions may need to rely on smaller, nonrandomized trials. Thus, in our smoking cessation example, ample evidence exists for the benefit of smoking cessation pro-

grams in the general population, such that the USPSTF found several specific types of smoking cessation interventions to be effective [25], including brief advice by a medical professional, office prompts, and media campaigns. Yet there is unlikely to ever be a randomized trial of the effects of a smoking cessation program in each cancer patient population, let alone cancer subtype, and among families and caregivers for the effects on mortality. Whereas the Emmons et al. [21] study found a significant benefit for the peer counseling intervention, the intervention has not been tested in other survivor groups. Yet we would not argue to withhold cessation services for smokers based on a lack of population-specific randomized trial evidence because it is reasonable to assume that the benefits outweigh the risks, particularly because other smoking cessation interventions, such as that of Gritz et al. [26] in head and neck cancer patients, have been shown to be effective. Therefore, it would be reasonable to implement a program similar to evidence-based programs for all cancer survivors and families. The value of implementing smoking cessation programs for cancer survivors without randomized trials for each intervention and each specific cancer diagnosis, particularly those with a clear link to smoking as a cause, may seem relatively straightforward. Greater challenges often come when considering other lifestyle factors.

The recently issued American College of Sports Medicine guidelines for exercise in cancer survivors provide an informative example [27]. The expert roundtable concluded that exercise is safe for cancer survivors, with evidence at the highest level for breast (during and after treatment), prostate, and hematologic cancers. However, randomized controlled trial data were not always available, particularly for non-breast cancer populations. There was insufficient evidence to generate specific evidence statements in colon and gynecologic cancers, though the report summarized current observational data and found it reasonable to extrapolate safety based on the available evidence. However, despite the body of evidence being sufficient to demonstrate high certainty for benefit for some outcomes, many questions, including those related to the type, dose, and duration of exercise, remain unanswered. This suggests both a need for greater research and a need for institutions to manage expectations regarding the available evidence base in program development and evaluation.

Because cancer survivors are at a higher risk for other chronic diseases, programs that offer nutritional recommendations and counseling on weight control should also to be considered [28–33]. There is limited evidence regarding complementary or alternative medicine program types/content.

Table 3. Implementation outcomes				
Implementation outcome	Level of analysis			
	Patient	Family	Provider	Organization
Acceptability	X	X	X	
Adoption			X	X
Appropriateness	X		X	X
Feasibility			X	X
Fidelity			X	
Cost of implementation			X	X
Penetration				X
Sustainability				X

Adapted from Proctor et al. [9].

Metrics for Evaluation

With the implementation of any treatment or survivor program, an essential component of the process must be evaluation and feedback to improve outcomes. Accordingly, the fourth step is to identify metrics for evaluating potential programs. Metrics can be both evidence and value based. A taxonomy for implementation outcomes was set forth by Proctor et al. [9] (Table 3). Institutions may want to ask questions such as: What level of evidence is needed to justify implementing a program? Under what circumstances should a program be implemented without an evidence base (appropriateness)? If intervention is effective, is it feasible (feasibility)? Is it sustainable (sustainability)? Is it acceptable to stakeholders (acceptability)? Are there staff and resources to support it (feasibility, sustainability)? If not, can they be hired (feasibility)? Are research programs included (penetration, adoption)? (Research components often provide support for programs). If yes, are they differentiated in some way?

The evaluation of programming needs to be a systematic decision given limited resources. Clearly, articulating the criteria helps set expectations and improves the quality of programming and the appropriate use of resources. Returning to the smoking cessation example, we listed numerous short- and long-term individual benefits to smoking cessation, some or all of which may not be easily assessed. However, calls to a quitline and attendance at cessation groups are metrics of interest and survivor smoking rates are a straightforward metric of program success. In the exercise example, the exercise guidelines focused on moderate intensity activity and drew largely on studies that prescribed walking or employed cycle ergometers. Programs like yoga, which include a movement component, were not evaluated. Yet many cancer centers offer yoga programs because interest is often high. As a result, institutions may

want to include it because interest is high and evidence is emerging that it is safe, although the benefits are not well articulated. However, in a limited resource environment, offering a program with a stronger evidence base, such as walking, may be more likely to achieve other goals, for example, improving quality of life or reducing mortality.

In addition to metrics of desired outcomes, institutions should also plan to evaluate the potential for unintended negative and adverse outcomes of their programs. Programs are not always without risk and institutions need to be aware of the risks associated with some offerings. Although that doesn't mean these programs shouldn't be offered, reviewing and understanding risks and communicating them to patients is important. Institutions should also consider cost and cost-effectiveness analyses. Articulating the time to breaking even in expenditures or the time institutions are willing to cover program costs is a key part of asset allocation. Again, the fact that programs are costly doesn't negate their merit, but articulating the expectations and analyzing the results is key to effective planning.

Implementation

Although implementing the program itself may seem straightforward, there is a large body of scientific research on the most effective ways of implementing evidence-based interventions and programs to achieve maximum benefit. The success of an evidence-based program that meets a stated goal depends on other implementation outcomes. These should be evaluated—in particular, acceptability, sustainability, and penetration [9]—as illustrated below. A program may have a strong evidence base for its effectiveness and high acceptability among stakeholders, but if costs are so high as to make the program not sustainable, the program will ultimately be an implementation fail-

ure. We draw on the work of Proctor et al. [9], who have offered several models for the potential success of program implementation. These include:

Implementation success = f of effectiveness + acceptability + sustainability (low).

Implementation success = f of effectiveness + acceptability + potential to improve care + penetration.

Clinicians may also draw on their experience translating results from efficacy trials to programs in the clinical care setting. Criteria that might be included in such an equation include program effectiveness (i.e., the evidence base), acceptability (among patients and providers), sustainability (including cost), quality improvement, and penetration. For smoking cessation, the effectiveness of the program includes many possible outcomes, such as a reduction in smoking rates, symptoms, or side effects, improved quality of life, reduced rates of recurrence, and improved mortality. These should have been articulated during the program identification phase as meeting one of the goals stated in step two. Acceptability should be assessed from the perspectives of both patients and providers, and might be measured by attendance, referrals, satisfaction surveys, or reach to specific targeted population subgroups (e.g., a disease group or individuals residing in a given geographic area). Sustainability is a resource question and may include financial, personnel, or space resources. The potential to improve care may also relate to satisfaction surveys or survival rates. Penetration examines the ability of the program to be disseminated to community or partner locations. (See additional comments on the smoking example in Table 1.)

Evaluation

Evaluation of the program draws on previous steps, pulling together the stated goals, metrics, and processes and occurs during and after implementation. Because programs typically take time to achieve desired aims, a clearly articulated time line should be developed prior to program implementation. Institutions may want to evaluate a broad range of outcomes and programs with potential to fill gaps where existing programs don't meet needs or are unsuccessful. In smoking cessation programming, for example, upon evaluation, institutions may find that the particular groups considered at high risk or need (e.g., head and neck cancer patients) aren't

enrolling in the program. This may suggest a need for targeted recruitment/advertising or for programming limited to this population. For example, instead of offering a general smoking cessation group on a recurring basis, the cancer center may choose to implement a peer-led group limited to head and neck cancer patients one quarter of the year and a more general non-peer led group the rest of the year, addressing cost, reach, and attendance concerns. Cost analysis might reveal that the upfront expenses associated with implementing smoking cessation programs are offset over a relatively short period of time, perhaps by decreasing follow-up care visits for complications [34]. Evaluation results should always be reported back to stakeholders for ongoing feedback.

CONCLUSION

Moving from evidence to practice to implement programs that support survivors requires planning that sets expectations and metrics for long-term evaluation. Many lifestyle factors known to determine the risk for recurrence, other chronic diseases, and mortality have been evaluated in the primary prevention setting but not in the setting of cancer patients who may be more highly motivated to change their smoking, diet, and physical activity and improve their weight.

By identifying potential gaps in the implementation and evaluation cycle we might more quickly move to widespread high-quality programs for cancer survivors. By providing a structure for planning these services, we aim to speed broadscale provision of services to survivors.

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