Clinical Practice Guidelines for the Psychosocial Care of Cancer Survivors
Current Status and Future Prospects*

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Upon completion of their primary treatment, many cancer survivors become “lost in transition,” and receive inadequate or, at best, poorly coordinated follow-up care. Unmet psychosocial and educational needs figure prominently among the concerns identified by survivors of adult-onset cancers in the post-treatment period. This article focuses on the role clinical practice guidelines could play in improving the quality of psychosocial care provided to these post-treatment survivors. After defining clinical practice guidelines and describing their development, the article provides an overview of existing clinical practice guidelines for the psychosocial care of cancer patients and identifies their strengths and weaknesses. A major weakness relevant to this article is that none of the existing guidelines focus on the post-treatment period. Two recent efforts in the field of cancer survivorship are identified that should stimulate and inform the development of guidelines for psychosocial care in the post-treatment period. One effort is the growing movement to implement survivorship care planning at the end of primary treatment. Assessing and addressing unmet and anticipated psychosocial needs have been identified as major components of survivorship care planning. The other effort is the release by the Children’s Oncology Group of Long-term Follow-up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. These guidelines provide a useful model of how guidelines for the psychosocial care of survivors of adult-onset cancers might be developed, organized, and implemented. Cancer 2009;115(18 suppl):4419–29. © 2009 American Cancer Society.

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Stimulated by their awareness of problems summarized in 2 landmark reports,1,2 clinicians and researchers are seeking ways to improve the quality of care provided to survivors of adult-onset cancers after the completion of their primary treatment. These individuals, referred to here as post-treatment survivors, face numerous challenges to restoring and maintaining their health and well-being as they transition from...
the primary treatment period to the follow-up period. Unfortunately, many of these survivors become “lost in transition,” resulting in their receiving inadequate or, at best, poorly coordinated care. Unmet psychosocial and educational needs figure prominently among the concerns identified by post-treatment cancer survivors. Problems such as these, however, are not unique to the post-treatment period and are known to exist during all phases of cancer treatment.

There have been several efforts in recent years aimed at improving the quality of psychosocial care. The current article focuses on the role of clinical practice guidelines in improving psychosocial care specifically in the post-treatment period. After first defining clinical practice guidelines and describing their development, this article provides an overview of existing clinical practice guidelines for the psychosocial care of cancer patients and identifies their strengths and weaknesses. A major weakness relevant to this article is that none of the existing guidelines focus on the post-treatment period. Two recent efforts in the field of cancer survivorship are identified that should stimulate and inform the development of guidelines for psychosocial care in the post-treatment period. One effort is the growing movement to implement survivorship care planning at the end of primary treatment. Assessing and addressing unmet and anticipated psychosocial needs have been identified as major components of survivorship care planning. The other effort is the release by the Children’s Oncology Group of Long-term Follow-up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. The section focusing on psychosocial issues, though limited in scope, provides a useful model of how guidelines for the care of survivors of adult-onset cancers might be developed, organized, and implemented.

Overview of Clinical Practice Guidelines

A frequently cited definition states that clinical practice guidelines are “systematically developed statements to assist practitioners and patient decisions about appropriate health care for specific clinical circumstances.” The history of clinical practice guidelines dates back to the late 1970s, when the National Institutes of Health Consensus Development Program began issuing consensus statements. The goal in developing clinical practice guidelines is to improve the quality of health care by identifying and promoting the adoption of the best health care practices.

Efforts to develop clinical practice guidelines can be viewed as part of a larger effort to promote evidence-based medicine. The field of evidence-based medicine arose, in part, to address problems with the quality of health care. Numerous reports and publications have shown that many patients fail to receive the care shown in clinical research to be effective for their disease or condition. An important example is a widely cited study that found that medical patients typically received only 55% of the care that would be recommended for them based on their history and health status.

Like many frequently used terms, evidence-based medicine has been defined in different ways. According to its major proponents, the practice of evidence-based medicine involves integrating individual clinical experience with the best available external clinical evidence from systematic research. Delivery of health care based only on clinical experience is viewed as running the risk of becoming rapidly out of date to the detriment of patients. On the other hand, without the benefit of clinical experience, the delivery of health care is viewed as running the risk of becoming tyrannized by evidence that is inapplicable to or inappropriate for an individual patient. As noted by the same proponents, the evidence that should be used to practice evidence-based medicine is not limited to randomized controlled trials (RCTs) or meta-analyses of the research literature, even though these are recognized as the “gold standard” of clinical research evidence. In many instances, no RCT or meta-analysis has been conducted that is directly relevant to a particular clinical decision. Under these circumstances, practice should be guided by the next best available external evidence.

Development and dissemination of clinical practice guidelines should have effects on health care consistent with the goals of evidence-based medicine. At a minimum, the guidelines should provide a description of appropriate care based on the best available evidence and a broad consensus. A side benefit is that the process of developing guidelines is likely to highlight shortcomings of the existing evidence base and, thus, identify directions for future research. Beyond this, the adoption of clinical practice care guidelines should reduce inappropriate variation in practice, provide a more rational basis for referrals to other health care professionals, and promote more efficient use of resources. Evaluating the extent of adherence to clinical practice guidelines is also useful because...
the information yielded may identify the need for and serve to guide quality improvement activities. Taken together, these efforts should ultimately yield better clinical outcomes.

Procedures for developing clinical practice guidelines have evolved over the years. Many early guidelines were developed, somewhat informally, by relying primarily on expert clinicians to identify and summarize the best available scientific evidence. As the field has evolved, the guideline development process has become more formal, in part, to ensure the systematic identification and rigorous appraisal of all relevant research. A full description of recommended procedures for developing clinical practice guidelines is beyond the scope of the current article. Readers interested in this topic are directed to a recent review that evaluated several guides and handbooks for developing evidence-based clinical practice guidelines. Table 1 summarizes 4 phases and 14 elements considered by the authors of this review to be central to the guideline development process.

### Table 1. Key Phases and Elements of Clinical Practice Guideline (CPG) Development

<table>
<thead>
<tr>
<th>Phases of Development</th>
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<tr>
<td>Preparing for CPG development</td>
<td>Selecting topic</td>
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<td>Determining the scope of the CPG</td>
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<td>Identifying and adapting existing CPGs</td>
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<td>Forming a multidisciplinary guideline development group</td>
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<td>Involving consumers</td>
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<td>Systematically reviewing the evidence</td>
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<td>Systematically searching</td>
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<td>Including and/or excluding identified research</td>
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<td>Appraising research</td>
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<td>Drafting the CPG</td>
<td>Developing recommendations</td>
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<td>Developing an implementation strategy</td>
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<td>Consulting on the draft CPG</td>
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<td>Writing of summary versions of the CPG</td>
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<tr>
<td>Reviewing the CPG</td>
<td>Planning for evaluating the impact, revising, and updating of the CPG</td>
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Adapted from Turner et al. 2008.

Quality of Psychosocial Care for Cancer Patients

In 2007, the Institute of Medicine (IOM) published a report titled, “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs.” One of the report’s major conclusions is that despite good evidence for the effectiveness of services in meeting patients’ psychosocial needs, cancer care often fails to address these needs. The reasons for this failure are many and include the tendency of oncology care providers to underestimate distress in patients and to not link patients to appropriate services when needs are identified. To address these problems, the report recommends that provision of appropriate psychosocial health services be adopted as a standard of quality cancer care. Psychosocial health services are defined as psychological and social services and interventions that enable patients, their families, and their health care providers to optimize biomedical health care and manage the psychological and social aspects of illness and its consequences. To ensure the appropriate and effective delivery of psychosocial health services, the report specifies a model in which processes are in place to 1) identify psychosocial needs, 2) link patients and families to needed services, 3) support patients and families in managing the illness, 4) coordinate psychosocial and biomedical care, and 5) follow up on care delivery to monitor the effectiveness of services and make modifications if needed.

These recommendations are consistent with those contained in the Cancer Service Guidance on Supportive and Palliative Care developed in the United Kingdom by the National Institute for Clinical Excellence (NICE) and in the Clinical Practice Guidelines for the Management of Distress developed by the National Comprehensive Cancer Network (NCCN). Similar to the IOM report, the 2004 NICE report concluded there are wide variations in the quality of supportive and palliative care,
with many cancer patients not receiving services that could benefit them.\textsuperscript{16} The bulk of the document comprises a series of recommendations and descriptions of various service models designed to ensure that patients and their families receive support and care to help them cope with cancer and its treatment at all stages. For example, similar to the IOM report,\textsuperscript{3} the section focusing on psychological support recommends that providers ensure that all patients undergo systematic psychological assessment at key points in their illness and have access to appropriate psychological support.\textsuperscript{16} The report then identifies a 4-level model of increasingly intensive psychological assessment and intervention that could be used to achieve the recommendation.\textsuperscript{16}

The NCCN guidelines,\textsuperscript{17} first issued in 1999 and updated annually, were developed based on the recognized need for better management of distress and with the intent of promoting best practices for the psychosocial care of cancer patients. Although too detailed to be fully summarized here, the NCCN guidelines are presented in the form of clinical pathways that describe recommended procedures for evaluating patients and recommended uses of psychological, psychiatric, social work, and pastoral care services to treat a wide range of problems. Similar to the IOM report,\textsuperscript{3} the NCCN guidelines recommend that all patients be routinely screened to identify the level and source of their distress. The specific services and resources subsequently recommended are designed to be appropriate to the nature and severity of the problems identified through the initial screening and further evaluation.\textsuperscript{17}

By specifying standards of care and identifying clinical pathways, the IOM and NICE reports and the NCCN guidelines have the potential to improve the quality of psychosocial care received by cancer patients. However, each of these initiatives has limitations with regard to the use of evidence. With regard to the NCCN guidelines, many of the recommendations are identified as being based on lower level evidence that includes clinical experience.\textsuperscript{17} With regard to the NICE report, the authors acknowledge there is no formal evidence of the benefits of implementing the recommended 4-level model of psychological assessment and intervention.\textsuperscript{16} With regard to the IOM report, it is noteworthy that there is no explicit statement in the standards of care that the psychosocial care provided to patients should be evidence-based.\textsuperscript{3}

### Using Evidence to Guide Psychosocial Care

The current status of recommendations for the psychosocial care of cancer patients shows how much more needs to be accomplished to ensure that this care is evidence-based. Two issues can be identified that have hindered progress. The first involves how the existing evidence base in psychosocial oncology has generally been used. The second involves notable gaps in the existing evidence base.

Systematic reviews and meta-analyses of the existing evidence base often focus on providing an overall conclusion regarding the efficacy of psychosocial interventions for cancer patients. Given the heterogeneity of the interventions studied and the difference in clinical characteristics among patients participating in different studies, these overall conclusions are of limited value to everyday clinical practice. An approach that may be more useful for efforts to translate research into practice would be to use the research findings to derive specific evidence-based recommendations. The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer issued in 2003 by the National Breast Cancer Centre and the National Cancer Control Initiative in Australia\textsuperscript{18} exemplify this approach. These guidelines are presented as a series of recommendations, accompanied by identification of the levels and sources of research support for each recommendation. Although not the focus of the guidelines, several of the recommendations are relevant to post-treatment cancer survivors. For example, the recommendation that depression be managed using combinations of supportive psychotherapy, cognitive and behavioral techniques, and pharmacotherapy pertains to patients regardless of whether they were in the primary treatment period or the post-treatment period. However, many of the recommendations are organized around specific phases of cancer treatment (eg, preparing patients for potentially threatening procedures) and points in the disease process (eg, support towards the end of life) that are of limited relevance to post-treatment cancer survivors. Application of these guidelines to the care of post-treatment survivors is also limited by the finding that no recommendations are offered that are specific to the post-treatment period or that focus on issues common in the post-treatment period (eg, fear of recurrence, relationship problems, and problems with return to work).
Three notable gaps can be identified that have limited the use of existing evidence to guide the psychosocial care of post-treatment survivors. First and foremost, few intervention studies have focused on post-treatment survivors. A recent systematic review found that only 8% of studies of psychosocial interventions for anxiety or depression recruited samples of patients not currently receiving treatment. Although research suggests cognitive-behavioral therapy is effective in relieving anxiety and depression in the post-treatment period, too few studies have been conducted to adequately evaluate other types of intervention for psychological distress. A related issue is that few interventions have been developed and evaluated for other challenges commonly faced by post-treatment cancer survivors, such as fatigue, cognitive problems, marital and family problems, and employment-related problems.

The general lack of research on patients experiencing clinically significant levels of symptoms such as anxiety, depression, and fatigue is another notable gap in the evidence base. For example, a recent systematic review found that only 5% of psychosocial intervention studies limited their eligibility to cancer patients experiencing some degree of anxiety, depression, or psychological distress. In addition to limiting statistical power to detect intervention effects, the lack of eligibility criteria based on current levels of anxiety, depression, or fatigue raises questions about whether findings reported are generalizable to patients experiencing clinically significant symptomatology.

A third gap is the general lack of research on integrated models of care delivery. As noted previously, the NCCN guidelines describe a model of care that features screening to identify patients’ level and source of distress, followed by the selection and implementation of appropriate intervention strategies and follow-up evaluations of patients’ status. This approach contrasts sharply with the format of most RCTs of psychosocial interventions conducted with cancer patients. These trials have generally accepted participants regardless of their current level of symptomatology and have generally focused on psychosocial rather than pharmacological or combined modality interventions. Consequently, most of the evidence base in psychosocial oncology has little bearing on the NCCN model of care, a model that probably reflects how psychosocial care is organized and delivered in many oncology settings.

The gaps identified above partially explain why evidence-based guidelines currently do not exist for the psychosocial care of post-treatment survivors of adult-onset cancers. As more RCTs of psychosocial interventions are conducted with post-treatment survivors, the ability to formulate evidence-based recommendations for the psychosocial care of these patients will likely improve. However, studies that focus solely on testing interventions will not address the need for evidence-based models of integrated care delivery that both identify the psychosocial needs of cancer survivors in the post-treatment period and link them to interventions effective in addressing those needs.

Survivorship Care Planning

The problems that cancer patients experience as they transition from the primary treatment period to the post-treatment period were the focus of a 2003 President’s Cancer Panel report titled, “Living Beyond Cancer: Finding a New Balance” and a 2006 IOM report titled, “From Cancer Patient to Cancer Survivor: Lost in Transition.” With regard to the psychosocial aspects of cancer survivorship, both reports observed that the current state of patient education about cancer, its treatment, and survivorship needs is inadequate. In addition, both reports concluded that the psychosocial and support needs of many survivors, their caregivers, and their family members are not being met.

One of the key recommendations provided in these reports can be viewed as a model for the integrated delivery of psychosocial care to post-treatment survivors. Specifically, the reports recommend that patients completing primary treatment be provided with a Survivorship Care Plan. In addition to describing the patient’s disease characteristics and the cancer care they received, this document should include a description of follow-up care that incorporates available evidence-based standards of care. Major components of this plan identified in the reports include a description of recommended cancer screenings and other periodic tests and examinations, and information about signs of recurrence and second tumors, possible late and long-term treatment effects, and effective...
chemoprevention strategies for secondary prevention. Several other components that feature prominently in the plan can be viewed as falling within the domain of psychosocial care. For example, the reports advise that patients receive information about the possible effects of their disease on marital/partner relationships, sexual functioning, parenting, financial status, insurance status, and employment status. Patients should also receive recommendations for healthy behaviors that include advice about diet, exercise, sunscreen use, and smoking cessation. To address these and other issues identified, the reports indicate that the plan should include referrals to specific follow-up care providers, support groups, and/or the patient’s primary care provider. Along with referrals, patients should receive a listing of cancer-related resources (eg, major cancer support organizations) and sources of additional information (eg, Internet Web sites).

Subsequent to the completion of these reports, the IOM convened a workshop devoted to advancing the implementation of Survivorship Care Plans. The proceedings of this workshop provide additional details about the content of Survivorship Care Plans and the processes for developing and using them in routine clinical practice. A full description of the information contained in the workshop proceedings, even just those parts relating to psychosocial care, is well beyond the scope of the current article. In its place, the current article attempts to distill information contained in the workshop report into a proposed clinical pathway for the psychosocial care of post-treatment cancer survivors (see Fig. 1).

As patients near the end of their primary treatment, a psychosocial evaluation should be conducted to identify those issues that would need to be addressed in this aspect of the Survivorship Care Plan. The evaluation would likely be conducted concurrent with a medical evaluation designed to identify other issues that would need to be addressed in the plan. In both cases, the goal is to generate a plan personalized to the patient’s specific disease and treatment characteristics and identified needs. To the greatest extent possible, the format of the psychosocial evaluation should draw upon existing evidence-based recommendations and its content should rely on well-validated screening instruments and assessment tools. Key components of the psychosocial evaluation would include an assessment of the patient’s psychological distress as well as other symptoms common in cancer survivors that may respond to psychosocial interventions (eg, pain and fatigue). The assessment should also address major areas of functioning including role, social, and family functioning and identify any practical problems (eg, finances, child care, and transportation) that would complicate the patient’s ability to receive recommended survivorship care. In addition, an assessment of current health habits (eg, dietary behavior and physical activity) and substance use (eg, tobacco and alcohol) would be necessary to formulate recommendations for lifestyle modification. Finally, the assessment should evaluate patients’ current levels of knowledge about their disease and its treatment and their desire for additional information about these topics and about specific aspects of survivorship. For some patients, this evaluation may need to determine if they have been made aware of the possible usefulness of genetic counseling and/or testing for cancer susceptibility for themselves or family members.

In many instances, instruments already exist that could be used to conduct the major elements of the end-
of-treatment psychosocial evaluation outlined above. For example, the Distress Thermometer, a measure that has been studied extensively with patients in various phases of cancer treatment,\textsuperscript{21} would appear to have potential as an initial screen for psychological distress at the end of treatment. Other portions of the end-of-treatment psychosocial evaluation may require the development of new measures. Methods for assessing patients’ and their caregivers’ unmet psychosocial and supportive care needs is one such area. A 2004 systematic review of needs assessment measures for cancer patients and their families identified no instruments targeting survivorship.\textsuperscript{22} Since the publication of this review, a set of measures designed specifically to assess the unmet needs of cancer survivors and their partners has been developed.\textsuperscript{23,24} Preliminary evidence suggests these measures have favorable psychometric characteristics and merit further study to evaluate their clinical utility.

The results of the evaluation performed should subsequently inform the specific recommendations that comprise the psychosocial component of the Survivorship Care Plan. Depending upon the findings, patients may need referrals for management of distress or other symptoms, receipt of social services, advice regarding legal or financial concerns, and/or assistance with lifestyle modification. The evaluation should also identify personalized information to be delivered to the patient to enhance their knowledge and understanding of the issues or problems they are currently facing or may likely face as a consequence of their disease and the specific treatments they received. For example, women treated with chemotherapy for early stage breast cancer who are experiencing fatigue at the end of treatment might be alerted to the possibility that their fatigue may persist for months or years based on evidence from longitudinal research.\textsuperscript{25} They might also be advised about interventions, such as cognitive-behavior therapy,\textsuperscript{26} shown to be effective in relieving fatigue in the post-treatment period. As part of the process of preparing for survivorship, patients would also receive information about resources available in their community (eg, support groups sponsored by cancer service organizations) and on the Internet designed specifically to assist post-treatment survivors. Examples of Internet resources include “Facing Forward: Life After Cancer Treatment” developed by the National Cancer Institute\textsuperscript{27} and “LIVESTRONG Survivor Care” developed by the Lance Armstrong Foundation and several partner organizations.\textsuperscript{28}

For those post-treatment survivors identified as having problems, issues, or needs that can be addressed with psychosocial care, the intervention(s) they receive should be supported by research evidence. For example, survivors experiencing clinically significant depression or anxiety should be treated with pharmacological and/or psychosocial interventions of demonstrated efficacy. Similarly, survivors who would benefit from changes in their diet or physical activity should be guided to programs shown to be efficacious in achieving goals consistent with American Cancer Society guidelines for nutrition and physical activity after cancer treatment.\textsuperscript{29} Ideally, the intervention(s) selected should have been evaluated and found to be efficacious in RCTs conducted with post-treatment cancer survivors. In the likely absence of such evidence, it may be necessary to rely on RCTs or lower level evidence from research conducted with patients undergoing primary cancer treatment or patients with other health conditions.

Appropriate follow-up and reevaluation should be considered essential components of any attempt to implement a Survivorship Care Plan. Follow-up provides an important opportunity to determine whether patients received or used the services that were recommended and, if so, to determine if the desired results were achieved. Information obtained at follow-up can be used to encourage adherence if initial recommendations were not followed or offer revised recommendations if the initial recommendations were carried out and did not yield the desired results. Finally, it is important to recognize that the psychosocial status of post-treatment survivors is dynamic and subject to change over time. Periodic reevaluation is necessary because new needs, problems, or issues are likely to arise at any point following the initial end-of-treatment evaluation.

In recommending Survivorship Care Plans, the IOM report acknowledged that the impact of developing these plans and providing them to post-treatment survivors has not yet been formally evaluated.\textsuperscript{1} The IOM report concluded that this approach simply makes sense and can be reasonably assumed to improve care unless and until evidence accumulates to the contrary.\textsuperscript{1} Other authors have argued that conducting research on Survivorship Care Plans is important because it could help to justify the resources required to implement care planning.
and could play a major role in defining how the plans are
developed, carried out, and refined. Among the major
issues that needs to be studied is whether survivorship care
planning actually reduces cancer-related morbidity and
mortality. With regard to the psychosocial aspects of Sur-
vivorship Care Plans, there is a need for studies that evalu-
ate whether procedures such as those depicted in Figure 1
yield the expected improvements in patient knowledge
and quality of life. Studies are also needed to identify if
survivorship care planning is effective in promoting adop-
tion of a healthier lifestyle. In addition to determining
whether survivorship care planning yields the desired out-
comes, these studies could identify optimal ways to con-
duct a psychosocial evaluation at the end of treatment and
to link patients to the resources and services that could
benefit them. Cost is an important factor to consider in
identifying optimal approaches to organizing and deliver-
ing survivorship care. Examination of the relative cost-
effectiveness of different models of integrated care delivery
is likely to identify those approaches with the greatest
potential for successful implementation. Given the many
barriers to providing psychosocial care, creation of an evi-
dence base that could guide clinical practice should be
viewed as an essential step in promoting the psychosocial
component of survivorship care planning.

Clinical Practice Guidelines for Pediatric
Cancer Survivors

The 2006 IOM report on adult cancer survivors was pre-
ceded by a 2003 report on pediatric cancer survivors. This
erlier report identified pediatric cancer survivors as
a vulnerable group with special health care needs and
called for the development of evidence-based clinical prac-
tice guidelines for survivorship care. In response to this
report and its recommendations, the Children’s Oncology
Group formed a taskforce to create long-term follow-up
guidelines for survivors of childhood, adolescent, and
young adult cancers. The product of this effort was first
released to the public in 2003 and has been updated peri-
dicularly. The procedures used to develop the guidelines
and an overview of their content were summarized in a
2004 publication. In brief, the guidelines comprised
recommendations for screening and managing late effects
that may arise as a consequence of the treatment of pediat-
tric malignancies, and they are designed to be applied to
patients who have been off treatment for a minimum of
2 years. The guidelines are described as being both evi-
dence-based and consensus-based. Research evidence was
used primarily to derive risk categories based on a review
of studies that have examined associations between treat-
ment exposure and late effects. Consensus was used pri-
marily to derive recommendations about how to screen
for late effects and how often to screen. Intervention rec-
ommendations are based on research evidence or, in its
absence, on a consensus of clinical experts.

An example will serve to illustrate how the guide-
lines are organized. Based largely on a review of research
evidence, the guidelines indicate that psychosocial disor-
ders (eg, social withdrawal and educational problems) and
mental health disorders (eg, depression and anxiety) are
potential late effects of any cancer experience (ie, regard-
less of specific treatment exposure). They also identify,
based largely on research, factors that may increase risk for
development of these late effects (eg, central nervous sys-
tem [CNS] tumors and CNS-directed therapy). Based
largely on consensus, the guidelines recommend that sur-
vivors undergo a psychosocial assessment on a yearly basis
that would include screening for psychosocial and mental
health disorders. Also based largely on consensus, the
guidelines recommend consideration of psychological
consultation, social work consultation, and psychotropic
medication as intervention strategies. Citations are pro-
vided to reviews and original research publications rele-
vant to these guideline recommendations. In addition,
readers are directed to “Health Link” documents, which
provide summary information about emotional and edu-
cational issues related to childhood cancer treatment that
can be used to facilitate patient education.

Conclusions and Future Directions

Undertaking the development of clinical practice guide-
lines for the psychosocial care of post-treatment survivors
of adult-onset cancers could serve several useful purposes.
First, the work involved in preparing for guideline devel-
oment (see Table 1) would require defining the scope of
the guidelines and reviewing existing guidelines to see if
they could be adapted to specifically address psychosocial
care in the post-treatment period. Second, the work
involved in systematically reviewing the evidence (see Ta-
ble 1) would yield valuable information about the
strength of research findings in this area and is likely to identify important gaps in knowledge.

Findings from recent systematic reviews of psychosocial interventions for adult cancer patients suggest that the state of research is not sufficient at this time to support development of guidelines for psychosocial care in the post-treatment period that are completely evidence-based.34 As noted previously, relatively few studies of psychosocial interventions have been conducted with patients in the post-treatment period, and few of these studies have focused on patients experiencing clinically significant psychological distress. In addition, there has been relatively little research examining integrated models of psychosocial care delivery in oncology settings. Notable exceptions include 2 studies35,36 that showed that the collaborative care approach to managing depression, found to be effective in primary care settings,37 can be successfully adapted for oncology settings. It should be noted, however, neither study focused on patients during the post-treatment period.

What progress can be made in formulating guidelines for psychosocial care in the post-treatment period given the limitations of the existing evidence base? The approach taken by the Children’s Oncology Group in developing their long-term follow-up guidelines5 illustrates how evidence- and consensus-based approaches to guideline development can be successfully combined. The general approach would be to formulate evidence-based recommendations whenever possible and to rely on consensus only when the evidence base is too limited. The current evidence base is probably sufficient to precisely identify the type, prevalence, and timing of many psychosocial late effects in post-treatment survivors of adult-onset cancers. The evidence base is also likely to yield useful findings regarding demographic, clinical, and psychosocial risk factors for these late effects. In addition, the existing evidence base is likely to yield many instruments with favorable psychometric features that could be used to screen for and assess psychosocial late effects. With regard to intervention strategies, it would appear that evidence-based recommendations could be developed for some psychosocial late effects (eg, fatigue) based on results of RCTs conducted with post-treatment survivors. For other psychosocial late effects (eg, cognitive difficulties) a consensus-based approach would probably be required in the absence of higher level research evidence. Finally, a consensus-based approach would probably be required to formulate recommendations for how psychosocial care should be organized given the current lack of research formally evaluating survivorship care planning or other integrated models of care delivery designed for the post-treatment period.

Any attempt to develop guidelines for psychosocial care in the post-treatment period must address the issue of sponsorship. The Long-term Follow-up Guidelines for Survivors of Child, Adolescent, and Young Adult Cancers5 were issued by the Children’s Oncology Group, one of the leading organizations in the world conducting large scale multi-institutional trials in pediatric oncology. This organization was able to draw largely on its membership to bring together recognized experts on the research topics that needed to be evaluated in formulating the guidelines. Beyond this, the organization appears to have provided logistical and financial support for the initial development of the guidelines. It also appears to be providing continued support for their dissemination and periodic updating. In the absence of the sponsorship and support provided by the Children’s Oncology Group, it is unclear whether these guidelines would have the visibility and credibility they possess or would even exist in their current form.

These considerations highlight the importance of identifying an institutional or organizational sponsor for the development of psychosocial guidelines in the post-treatment period. This issue is complex, however, because there is no single organization that is the equivalent of the Children’s Oncology Group for adult-onset cancers. The issue of sponsorship also raises the question of whether the psychosocial guidelines would be “freestanding” or part of a comprehensive set that also addresses other important aspects of survivorship care (eg, disease surveillance and detection and management of other late effects). As noted previously, selecting the topic and determining the scope is the first step in preparing for guideline development (see Table 1). A narrow scope (ie, developing freestanding guidelines) would assure that the psychosocial evidence base is considered in depth, but it may yield guidelines that are difficult to integrate with those covering other aspects of survivorship care. A broad scope (ie, developing comprehensive guidelines that include psychosocial issues) would promote a more unified approach to care, but it may have too large a focus to be undertaken by any single organizational sponsor.
One possible solution would be for several organizations to jointly sponsor the development of a comprehensive set of survivorship guidelines that focused initially on one or two of the more common adult-onset cancers. After agreeing on a common framework and process for guideline development, each organization would then identify experts among their membership who would participate in the effort. The sponsoring organizations should include those representing the major oncology specialties (eg, medical, surgical, radiation, and psychosocial oncology) as well as those representing the interests of cancer survivors. Different panels would be formed to address the major issues of survivorship (eg, disease surveillance and psychosocial care), with an integration panel created to ensure that the guidelines produced were consistent and coordinated with each other. In addition to bringing together the expertise necessary to produce a comprehensive set of guidelines, this collaborative approach could lay the groundwork for the guidelines to be effectively disseminated and implemented to the public and the medical community.

**Conflict of Interest Disclosures**

The author made no disclosures.

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