The period after completing primary and adjuvant cancer treatment until recurrence or death is now recognized as a unique phase in the cancer control continuum. The term “survivorship” has been adopted to connote this phase. Survivorship is a time of transition: Issues related to diagnosis and treatment diminish in importance, and concerns related to long-term follow-up care, management of late effects, rehabilitation, and health promotion predominate. In this article, we explore the unique challenges of care and health service delivery in terms of the interface between primary care and specialist care during the survivorship period. The research literature points to problems of communication between primary and specialist providers, as well as lack of clarity about the respective roles of different members of the health-care team. Survivorship care plans are recommended as an important tool to facilitate communication and allocation of responsibility during the transition from active treatment to survivorship. Research questions that remain to be answered with respect to survivorship care plans and other aspects of survivorship care are discussed.


Figure 1. Types and transitions in care that constitute the process of care across the cancer continuum.
Challenges at the Interface of Primary and Subspecialty Care for Cancer: Current Practice Patterns From Treatment Through Follow-Up Monitoring

Cancer recurrence and late effects of cancer treatments are important and ongoing concerns for cancer survivors. However, the majority will actually die of other causes. For example, an analysis of the causes of death for breast cancer patients who did not die of their cancer indicates that many of the major causes of death are from conditions that are modifiable through lifestyle changes (eg, heart and respiratory disease) or screening (eg, colon cancer) (9). Consequently, care for general medical and preventive health issues are equal in importance to care for the index cancer. We review here some of the problems experienced by cancer survivors in receiving various types of health care and discuss how survivorship care plans can be an important tool to address some of these problems.

Evidence indicates that cancer survivors may be less likely than age-matched noncancer patients to receive recommended care for chronic conditions across a wide range of diseases (6). A study examining 44 quality-of-care indicators in 14,884 five-year survivors of colorectal cancer compared with matched controls found that despite having more medical contacts, survivors were overall less likely to receive recommended follow-up for chronic conditions, such as angina, congestive heart failure, and chronic lung disease, and to receive less of some types of preventive care. For example, diabetic cancer survivors were less likely to have preventive eye examinations, and the data showed a trend toward less intensive monitoring of HbA1c (6). This effect is not universally observed, however. Another study of 5,965 five-year breast cancer survivors found that they actually received more health maintenance care, such as influenza vaccination and cholesterol screening, than did matched controls without a history of cancer. In this study, despite having more medical contacts and demonstrated access to care, important disparities also existed based on race and wealth (10).

These and other studies have found that patients who were followed only by primary care physicians were more likely to receive preventive interventions directed at noncancer conditions, whereas those followed by oncologists were more likely to receive interventions directed at cancer surveillance (6,10,11). These findings may reflect different assumptions by patients and providers about providers’ roles after cancer treatment. For example, some patients may expect their oncologist to effectively become their primary care physician, but the oncologist may be unaware of this expectation. Although some oncologists are willing and able to act as a primary care physician, surveys have shown that most are not (12). Indeed, a recent survey of cancer survivors and their physicians found significant discordances in expectations about many aspects of care.

When the patient is ready to transition from active treatment to follow-up care, it is essential that both the patient and the primary care physician are aware of who is primarily responsible for future care (35). The studies cited above, which show that recommended cancer surveillance is more likely to occur when an oncologist is involved in survivorship care, illustrate this point (6,9,11). Underuse of cancer surveillance by primary care physicians may reflect an assumption that an oncologist has remained involved and is leading this aspect of care. In some cases, lack of appropriate surveillance may contribute to negative patient outcomes.

COMMENTS

From a Survivor

The fact that primary care physicians are more likely to provide preventive care suggests that oncologists may not see this as part of their area of responsibility. If a primary care physician is not actually involved, or the patient has looked to their specialist to provide all care, these important services may not be delivered, much to the detriment of the patient. Roles are likely even more blurred when it comes to issues, such as the effect of cancer and its treatment on sexuality, psychosocial distress, or employment concerns, potentially leaving these problems unaddressed.

Most striking is the mismatch in expectations about which provider is to be responsible for screening for cancers other than the index one (eg, which provider is responsible for arranging colonoscopy and Papanicolaou smears in a breast cancer survivor). Survivorship care plans can be used to resolve some of this mismatch by clearly identifying the responsible provider for each aspect of care and ensuring that patients and providers are aware of the allocation of responsibility (11).

From a Survivor

From a Survivor

As a young adult cancer survivor, the issues I’m concerned with are different than those for children or older adults. I must consider issues such as timing pregnancy (and managing breastfeeding) in between colonoscopies, how my cancer affects my children’s need for screening, and how to stay abreast of the research that may change such decisions in the future. It is a challenge to manage how this interacts with my overall health, as that will also change as I get older.
on responsibility for cancer survivorship care (7,15,16). Several randomized controlled trials have shown that both clinical and quality-of-life outcomes are unaffected when the primary care physician is primarily responsible for routine follow-up care (2,16,17). The need to integrate management of the index cancer, comorbid conditions, and general preventive care underscores the importance of providing comprehensive coordinated care (18,19).

From the examples given above it can be seen that communication is at the core of many of the problems at the interface between primary care and specialist care for cancer (14). Cancer care is frequently multidisciplinary and largely takes place in isolation from primary care physicians. Although primary care physicians are probably involved during the initial cancer diagnosis, they may not be fully aware of the treatments and other modalities of care (such as psychosocial care) that ensue (12,14,15). A clear allocation of responsibility can improve communication at the interface between primary and oncology care. Some patients themselves may wish to take a more active role at the interface of primary and specialty care during this phase of their care.

Potential Solutions: Insights From Research

Several models and tools have been proposed to meet the complex health-care needs of cancer survivors through better integration between primary care and specialist cancer care. Oeffinger and McCabe (20) propose a shared care model that attempts to rectify the current problems of unclear allocation of responsibility and poor communication.

The model describes which tasks and communication issues are primarily the responsibility of primary care vs specialist cancer care along the care trajectory from diagnosis to survivorship. An important tool to achieve this model is the survivorship care plan. Survivorship care plans, as envisioned by IOM, are designed to address potential deficiencies in communication by explicitly laying out for patients and all involved providers a plan for surveillance and other care in the future (Appendix 1). Ideally, the plan would be used as a general guide for the future as well as a resource for use during specific visits. At this point, however, it is not clear exactly who should be responsible for developing these plans. Nevertheless, the patient and oncologist (or other member of the oncology team) could use the plan to review a summary of the diagnosis and the treatment received, discuss recommendations for surveillance for cancer recurrence, and discuss recommendations for routine health maintenance unrelated to the cancer. This also would be an opportunity to educate the patient about psychosocial support and other resources available for cancer survivors. The treatment summary would indicate the cancer diagnosis, histology, and stage, and list the different primary treatments given and their dates. The treatment summary also should identify and provide contact information for those who provided oncology care and, ideally, identify a key provider for follow-up care. The optimum provider for follow-up care may be different for different types of cancer. For example, for breast cancer patients, there is good evidence that the provider can be either an oncologist or a primary care physician (21,22). In contrast, anal cancer requires endoscopic surveillance, which should be done by a specialist. In most cases, however, many types of providers are able to deliver high quality of care. As a result, preferences of the patient and the involved providers can play a large part in determining who does what. The essential thing is that it is clear to the patient and all involved health-care providers who will be primarily responsible for what aspect of follow-up care.

The care plan should address recommendations regarding both cancer and noncancer care. By being specific to the patient, it is actionable by their providers. It is not reasonable to expect generalists to remain up-to-date on surveillance recommendations and potential side effects of new cancer treatments, but they are well able to act on specific information and implement a care plan. Recommendations for cancer surveillance can be found from several sources. The American Society of Clinical Oncology (ASCO) has evidence-based surveillance guidelines for breast and colorectal cancers that can be found at www.asco.org under the Quality Care and Guidelines tab. Consensus guidelines for surveillance for recurrence of other cancers after treatment are incorporated into the National Comprehensive Cancer Network (NCCN) guidelines, found at www.nccn.org. Unfortunately, no comprehensive guidelines have been developed for monitoring or managing long-term and late effects of cancer therapy for survivors of adult cancer.

However, the major issues can be extrapolated from the consensus guidelines of the Children’s Oncology Group, found at www.survivorshipguidelines.org. Long-term effects are those that first occur during cancer treatment and persist after completion of primary therapy, such as peripheral neuropathy from some chemotherapy drugs. Late effects are those that were not apparent during primary treatment but become apparent at some later time, such as bone loss and increased risk of hip fracture from pelvic radiation (23).

With respect to noncancer care, it has been suggested that completion of treatment for cancer may be a “teachable moment” (24) when patients may be more receptive to messages about health behaviors, such as quitting smoking or becoming physically active. Moreover, as mentioned above, it is important to know about age- and sex-appropriate screening recommendations for other cancers and other medical conditions and to ensure clarity about which provider will coordinate these activities. Lastly, the IOM
recommend that patients be given sources of information related to
to potential insurance, employment, and financial challenges.

Creating a survivorship care plan is a practical challenge, how-
ever (25). Although many providers can make important contribu-
tions, one of the patient’s oncology providers is usually in the
best position to lead it by virtue of specific knowledge of the
treatment received and professional knowledge of surveillance
and other recommendations related to the cancer and its treat-
ment. But these practitioners are busy, a counseling visit to
review these issues is not well reimbursed, and in the end, most
of the benefits accrue to the patient and other providers rather
than to the oncologist. At this point, it is also unknown whether
this saves money or costs money, and so it is unclear to payers
whether it is in their interests to fund this activity. Consequently,
widespread implementation of survivorship care plans will require
a culture change in which it becomes a required part of good
cancer practice. Patients and referring physicians, such as the
primary care physician, can help effect this change by demanding
a care plan.

Two randomized controlled trials of follow-up care for breast
cancer patients have shown that, when given what could be consid-
ered a brief survivorship care plan in the form of a clinical practice
guideline with explicit directions for follow-up care, primary care
physicians achieve the same outcomes as specialists (2,3,7,26,27).
These trials, which compared primary care physician follow-up
with oncologist follow-up, found that the delay in time to diagnos-
tic recurrence was the same (2), as was the rate of recurrence-re-
lated serious clinical events (7). Health-related quality of life was
unaffected, patient satisfaction was better (27), and both patient
and health service costs were less (28). Moreover, these findings
confirm the results of surveys showing that primary care physicians
are generally willing to take on this role (16,29). In both random-
ized controlled trials, almost all primary care physicians agreed to
provide exclusive follow-up care for their patients. Although such
a model may be particularly attractive for breast cancer, where the
evidence is strongest and the manpower concerns are greatest (25),
a trial with similar methodology that was directed at follow-up care
for colorectal cancer patients showed similar results (17). Another
important element of this research is that it confirmed the findings
of numerous observational studies that most recurrences are symp-
tomatic when detected and that patients present first to their pri-
mary care physician with symptoms, regardless of formal follow-up
arrangements (30,31).

There is no single best way that survivorship care must be
provided. The type of provider—specialists, generalists, physi-
cian-extenders, or combination of these in a “shared care” model
(19), or in a specialized survivorship clinic—is less important than
ensuring there is communication and coordination of care among
the multiple providers involved (18). Several tools, such as
complete survivorship care plans and individual elements of those
plans, such as clinical practice guidelines and structured consulta-
tion and discharge letters (32), can facilitate the process of
communication, provided that all members of the health-care
team are committed to improving coordination of care (33).
Information technology also may make an important contribution.
The article by Hesse et al. (34) in this supplement explores this
issue in depth.

**Future Research**

Survivorship care plans are viewed as the tool with the greatest
potential to address the problems at the interface between
primary care and specialist care during the transition period from
active treatment to survivorship because of their focus on improv-
ing communication. The IOM made the remarkably bold state-
ment that survivorship care plans “have strong face validity and
can reasonably be assumed to improve care unless and until
evidence accumulates to the contrary” (p. 5) (4). Despite this
strong statement, research on a range of questions about survivor-
ship care plans is still needed to make evidence-based recommenda-
tions. For example: Who should prepare the plan? Who reviews
it with the patient? How is it transmitted to the primary care
physician? Moreover, it is important to evaluate the impact on
outcomes from both the perspective of the patient and the health-
care system, as well as cost-effectiveness. One such evaluation
involving breast cancer survivors in a multicenter randomized
controlled trial is currently under way (Grunfeld et al., NCIC/
CBCRA grant #17423). It also would be valuable to study the
potential benefits of other forms of standardized templates, such
as structured discharge letters and clinical practice guidelines, as
adjuncts to care plans.

In addition to research on survivorship care plans, other
important areas require study. Different models for the organiza-
tion and delivery of survivorship care, from dedicated tertiary
care survivorship clinics to community-based nurse-navigators,
warrant evaluation. Do these different models improve coordi-
nated and comprehensive care or do they contribute to further
fragmentation of care?

Patient preferences and manpower implications also must be
considered. These efforts should eventually lead to the estab-
lishment of standards of care, clinical practice guidelines, and
quality-of-care measures related to cancer survivorship. To
date, this area has had a paucity of research. It is vital to under-
stand patients’ views of different models of survivorship care
and the optimum time for introducing a discussion about the
transition in care. An interesting research question would be the
potential value of the patient as the intermediary between
primary and specialist physician: Would this form of patient
empowerment lead to better outcomes or merely add to patient
burden?

**Conclusions**

The number of cancer survivors is growing exponentially.
Survivorship is increasingly recognized as a distinct entity within
the cancer care continuum, and the point of transition from
active anticancer treatment to survivorship is an important time
to set the stage for subsequent care. Empowering patients to take
responsibility for their own care and ensuring clarity around
where responsibility for cancer surveillance, general preventive
care, screening for other cancers, and management of comorbid
conditions lies will go a long way toward addressing current gaps
at the interface between primary and specialist care during the
transition from active treatment to survivorship. In most cases,
more important than the details of the plan is that it is clear to
all involved what has been done, what should be done going
Appendix 1: The Institute of Medicine survivorship care plan*

Upon discharge from cancer treatment, including treatment of recurrences, every patient should be given a record of all care received and important disease characteristics. This should include, at a minimum:

1. Diagnostic tests performed and results.
2. Tumor characteristics (eg, site(s), stage and grade, hormone receptor status, and marker information).
3. Dates of treatment initiation and completion.
4. Surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, or gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment.
5. Psychosocial, nutritional, and other supportive services provided.
6. Full contact information on treating institutions and key individual providers.
7. Identification of a key point of contact and coordinator of continuing care.

Upon discharge from cancer treatment, every patient and his/her primary health-care provider should receive a written follow-up care plan incorporating available evidence-based standards of care. This should include, at a minimum:

1. The likely course of recovery from acute treatment toxicities, as well as the need for ongoing health maintenance or adjuvant therapy.
2. A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed (and who should provide them).
3. Information on possible late and long-term effects of treatment and symptoms of such effects.
4. Information on possible signs of recurrence and second tumors.
5. Information on the possible effects of cancer on marital/partner relationship, sexual functioning, work, and parenting, and the potential future need for psychosocial support.
6. Information on the potential insurance, employment, and financial consequences of cancer and, as necessary, referral to counseling, legal aid, and financial assistance.
7. Specific recommendations for healthy behaviors (eg, diet, exercise, healthy weight, sunscreen use, immunizations, smoking cessation, and osteoporosis prevention). When appropriate, recommendations that first-degree relatives be informed about their increased risk and the need for cancer screening (eg, breast cancer, colorectal cancer, and prostate cancer).
8. As appropriate, information on genetic counseling and testing to identify high-risk individuals who could benefit from more comprehensive cancer surveillance, chemoprevention, or risk-reducing surgery.
9. As appropriate, information on known effective chemoprevention and behavioral strategies for secondary prevention (eg, tamoxifen in women at high risk of breast cancer; smoking cessation after lung cancer) and monitoring of adherence to these recommendations.
10. Referrals to specific follow-up care providers (eg, rehabilitation, fertility, psychology), support groups, and/or the patient’s primary care provider.
11. A listing of cancer-related resources and information (eg, Internet-based sources and telephone listings for major cancer support organizations).

References


* Reprinted with permission from From Cancer Patient to Cancer Survivor: Lost in Transition, 2005 by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, DC (4).


**Affiliations of authors:** Ontario Institute for Cancer Research and Department of Family and Community Medicine, University of Toronto, Toronto, ON, Canada (EG); Cancer Care Ontario, Ontario Institute for Cancer Research, University of Toronto, Toronto, ON, Canada (CCE).