

Chapter 2

What Is Quality Health Care for Cancer Survivors?

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Introduction

Defining Cancer Survivorship

The term “cancer survivor” has been used to identify different populations affected by cancer [1, 2]. The National Coalition for Cancer Survivorship (NCCS) suggests “an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life [3].” This definition, which has been adopted by the National Cancer Institute Office of Cancer Survivorship, covers family members, friends, and caregivers, who are also affected by the survivorship experience. It also acknowledges that cancer affects people for the rest of their lives. Traditionally, to “survive cancer” has meant to be cured of or to appear to be free from cancer. Measures such as 5-year disease-free (or overall) survival [2] have been deployed to mark out the survivor period. More recently, the meaning of “cancer survivorship” has been broadened to signify the period following potentially curative treatments; notably, the influential Institute of Medicine (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, focuses on this period [4]. This definition does not explicitly include family and caregivers, so we must remember that cancer also affects those close to the person with cancer. We must also remember that the survivor experience is a continuum, which includes diagnosis and treatment, and may also include recurrence, living with advanced cancer, and death.

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Importance of Continued Care for Cancer Survivors

There is increasing awareness of challenges that survivors may experience following completion of primary treatment. They may experience physical, psychological, and social consequences of cancer and its treatments [5–11]. Survivors may feel abandoned by their cancer treatment team and experience fear of cancer recurrence, uncertainty about the future, difficulties returning to work and social situations, financial problems, and issues managing long-term and late effects of treatment [5–11]. The risk of second or recurrent cancers is increased for survivors, who also face illnesses such as heart disease and arthritis that affect older populations [12]. Care beyond the period of acute treatment needs to include appropriate management of such problems to improve survivor outcomes [13, 14]. In its recommendations regarding the transition from cancer patient to cancer survivor, the IOM recommended that “health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care” [4]. This chapter provides a discussion of just what “the delivery of appropriate survivorship care” is.

Current Survivorship Care

Care of cancer survivors appears to be suboptimal [4]. Follow-up care between the oncology specialist (surgical, medical, and radiation oncologists) and primary care provider may be poorly coordinated, meaning that the survivor risks either duplication of effort or gaps in care. A too-narrow medical focus on surveillance for recurrence, metastases, or new primary cancers may overlook late physical and psychosocial effects, including the impact of cancer on the survivor’s life. Advice and strategies that promote healthy living and psychosocial well-being are rarely discussed; when they are, this is usually ad hoc, inconsistent, and without a sound evidence base [4, 15, 16].

Patients often lack necessary information and continuing support [7]. In Hewitt’s research on posttreatment cancer care, most survivors reported satisfaction with current medical care, but not with how their psychosocial needs were met. At the end of treatment they felt overwhelmed, but were rarely given written information [17].

I think it’s just one of those things that during the treatment period you’ve got a, like, a schedule that you’re running to, and everyone runs to that. There’s a plan.

And everyone knows, “Right, well, I can help this way by I’ll drive you to that chemo session. I’ll do this on it.” And everyone can say “Now, alright, you cook the meals this week; I’ll do it that week.” All that wonderful support that’s around you from your family and friends, you come out of treatment, when you get the sort of “OK, it’s all over,” no one knew quite what to do. And now, is it all just going to be magically better? And I was all prepared for the amount of time it was going to take for me to feel better after the chemo and that, because it took forever before I felt human again, and no one quite knew what to ask me to do at work, how much more to put back on me, all that sort of thing [6].

After my good news, a year after treatment, I spat up blood, and I went “Oh dear, it’s back.” I was taken in; they looked down and couldn’t find anything. Patted me on the head and sent me home. For the next five years I was waiting to be spitting up blood again, until I finally did. So I came back here, and they said, “Don’t worry about it. It happens.” Now, if somebody had told me that five years before, I wouldn’t have been worried about it coming back so much [6].

In a large Internet-based study conducted by the Lance Armstrong Foundation, 33% of survivors reported there were few or no resources available to deal with their emotional needs; 70% felt that their physician was unable to assist with identified nonmedical issues [18].

Importantly, optimal survivorship care does not begin as treatment ends. Optimal posttreatment outcomes are strongly influenced by experiences and interventions that take place much earlier, including at diagnosis and during treatment. Identifying and addressing supportive care needs early may result in improved outcomes [15, 16, 19]. For example, meeting informational needs and providing necessary practical and emotional support is likely to reduce distress following treatment completion and into the survivorship phase. Similarly, medical interventions during the treatment phase may prevent later consequences. For example, with appropriate intervention, it may be possible to reduce the risk of premature menopause, infertility, sexual dysfunction, and cognitive problems.

Over the past 15 years, there has been increasing pressure for better services for survivors:

- In 1996, the National Coalition for Cancer Survivorship established 12 principles for delivering quality cancer care [20].
- There has been extensive investigation into the types of changes needed to improve the quality of care, including the 2001 IOM report *Crossing the Quality Chasm: A New Health System for the 21st Century* [21].
- In 2005 the IOM released *From Cancer Patient to Cancer Survivor: Lost in Transition*, which comprehensively examines the need for improved care for survivors [4].

A Framework for Considering Quality Survivorship Care

The IOM Committee on Health Care Quality in America has defined essential features to guide the redesign of health-care processes [21]. These are shown in Table 2.1.

These general considerations provide a valuable framework for considering ideal care for cancer patients and survivors. Importantly, the above points do not impose a restricted consideration of patient needs. As noted, survivors may encounter a broad range of consequences as a result of cancer and its treatments. Some might clearly be considered within the scope of medical care (treatment of side effects, risk of late effects) and some within the broader scope of supportive care (dealing with fear of recurrence, adjustment issues); however, other issues, for

Table 2.1 Essential features to guide the redesign of health-care processes [21] (Reprinted with permission from the National Academies Press, Copyright [2001], National Academy of Sciences)

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- Care based on continuous healing relationships. The system should be responsive and accessible.
 - Customization based on patient needs and values. The system should have the capability to respond to individual patient choices and preferences.
 - The patient as the source of control. Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over decisions that affect them.
 - Shared knowledge and the free flow of information.
 - Evidence-based decision-making.
 - Safety as a system property.
 - The need for transparency.
 - Anticipation of needs. The system should not just react to events.
 - Continuous decrease in waste.
 - Cooperation among clinicians.
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example, returning to school or work or coping with financial consequences, may not be considered the focus of posttreatment care. Perspectives of the survivor, health-care provider, and payer may indeed be quite different regarding what constitutes quality survivorship care. It will be important to continue to debate the scope of “quality health care for cancer survivors.”

Considering the range of potential issues affecting survivors and the need for a broad focus, it is worthwhile to highlight the World Health Organization definition of health, that being “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity [22].” The emphasis on well-being accords with a notion of cancer as a chronic disease and the need for rehabilitation following active cancer treatments.

In addition to advocating for planned and coordinated care to manage the medical and psychosocial difficulties experienced by cancer survivors after completing treatment, the IOM report *From Cancer Patient to Cancer Survivor: Lost in Transition* attempted to further describe and “operationalize” the content of what survivorship care should involve. Four essential components of survivorship care were identified and are presented in Table 2.2 [4].

While these four components may have broad applicability, it should be remembered that every survivor will have a unique experience. Even patients with the same type of cancer may receive quite different treatments, be affected in very different ways, encounter individual difficulties, and be at risk of different consequences. This underscores the need to tailor follow-up to each individual survivor.

Prevention of Recurrent and New Cancers, and of Other Late Effects

Although survivors remain at a heightened risk of developing new cancers, this risk may be reduced through health promotion strategies [14]. There is increasing evidence to support the use of adjuvant medical treatments to reduce the risk of cancer recurrence. In addition, the period after treatment can be seen as a

Table 2.2 Four essential components of survivorship care

1. <i>Prevention</i> of recurrent and new cancers, and of other late effects
2. <i>Surveillance</i> for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects
3. <i>Intervention</i> for consequences of cancer and its treatment
4. <i>Coordination</i> between specialists and primary care providers to ensure that all of the survivor’s health needs are met

“teachable moment,” where changes to health and lifestyle may be more readily adopted in an attempt to prevent disease and ill health [4]. Improved diet, maintaining a healthy weight, ceasing smoking, and increasing physical activity may prevent secondary and recurrent cancers, and may reduce many of the physical and psychosocial consequences of cancer treatment [23, 24]. Information on recommended health and lifestyle strategies should be provided to all cancer survivors [4, 24]. Indeed, the second recommendation of the IOM report (and relevant to each of the four essential components of survivorship care) concerns provision of information: “patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This ‘survivorship care plan’ should be written by the principal provider(s) who coordinated oncology treatment. It is recommended that this service/procedure be reimbursed by third-party payors of health care [4].” It is possible that this coordinated effort would provide for a more systematic and even preventive service, reducing the need for mismanaged care.

Surveillance for Cancer Spread, Recurrence, or Second Cancers; Assessment of Medical and Psychosocial Late Effects

Ongoing surveillance is an essential component of follow-up care to ensure that new or recurrent cancers are detected at a time when treatment may be most effective [25]. Guidelines are not available for all cancer types and vary considerably in terms of their comprehensiveness. Many emphasize detection of cancer recurrence, but place little emphasis on the prevention, detection, and amelioration of the consequences of cancer treatments. Many of these guidelines provide inconsistent recommendations about the frequency, duration, and type of follow-up that is required for different survivor groups [25]. The third recommendation from the IOM report was that “Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector efforts [4].”

Surveillance is an ideal opportunity to monitor treatment efficacy and any ongoing physical or psychosocial consequences. It is also a time to provide continuing information and support. Surveillance may also help survivors to feel less anxious

about the possibility of cancer returning and more confident about what will happen to them in the future. Surveillance should be tailored, with individuals at high risk of treatment sequelae requiring a higher degree of surveillance [25]. Surveillance also provides an added opportunity to screen for general health issues, as many patients neglect other areas of health due to a heavy focus on cancer and recurrence [26]. Furthermore, it has been suggested that a full review of psychosocial and adjustment issues be incorporated into an optimal model of survivorship care [12].

Intervention for Consequences of Cancer and Its Treatment

Cancer survivors may require further assistance managing the physical and psychosocial effects of cancer diagnosis and treatment. Patients may have persisting, even long-term effects and be at risk of developing problems at a later time – late effects. Physical issues such as fatigue, pain, urinary and bowel issues, and hot flashes may be successfully managed with medical interventions or self-care strategies [6, 27]. A growing number of psychosocial interventions may improve symptom management and psychological issues as they arise and should be discussed as part of a tailored survivor consultation [28].

Coordination Among Specialists and Primary Care Providers

Follow-up care is often provided by a group of oncology specialists and primary care providers. This system has a number of strengths, if used effectively. Cancer screening services are received more reliably when specialists are involved; however, preventive services for other medical illnesses tend to be neglected [12]. This may be greatly improved when a primary care provider is also involved [12]. Coordinated care between oncologists and primary care providers is essential to ensure that all health needs are met [4, 29]. Regular, effective communication strategies are crucial to the success of such an arrangement. Care plans may assist. Clear delineation of roles is essential. Comprehensive care means that each of the above principles (detection, surveillance, and intervention) should be undertaken, but it is less clear how to optimally allocate these responsibilities in a shared care model.

Elsewhere we have suggested other elements of ideal survivorship care [30]. High-quality care would:

- Be comprehensive and accessible
- Include specialized services
- Be patient-centered
- Be tailored to meet individual needs
- Empower survivors to take a role in their own health management to the extent that they wished
- Be multidisciplinary and collaborative and include oncologists; primary care providers; nurses; rehabilitation specialists such as physiatrists, physical therapists, social workers and psychologists; and survivors and their families

- Recognize the transition from acute care to the community and be designed to facilitate this transition
- Use effective communication strategies to promote planned and coordinated follow-up
- Be holistic and address psychosocial as well as physical needs
- Encompass preventive as well as reactive health management
- Be evidence-based and supported by appropriate guidelines, policies, and research, to ensure that care is outcomes-focused, cost-effective, and sustainable

Defining and Measuring Quality Survivorship Care

The ultimate objective of good quality cancer care is to achieve desired outcomes for survivors. This includes not only surviving the cancer but also living well. Functional status, quality of life, and the personal cancer care experience emerge as critical and perhaps overlooked outcomes [31, 32]. Thus, important outcomes for cancer survivors include not only overall and disease-free survival but also functional status and quality of life, as well as their experience of care (satisfaction).

The IOM has defined *quality* as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge [33].” Of note, this definition refers to health services and health outcomes. Health systems overall tend to be oriented around the acute treatment of ill people, with lesser emphasis on prevention and rehabilitation. Cancer is a leading cause of death. Thus, research and clinical services have developed with the primary focus being effective treatment with the goal of cure. Quality frameworks have emphasized the treatment phase of the cancer journey and focused on safe, effective, well-coordinated medical care. Only quite recently has there been recognition of the posttreatment phase. Survivors may be affected by cancer and its treatments for many decades. As noted previously, survivors’ well-being may be strongly influenced by a broad set of consequences, including impact of the illness on work, education, finances, and relationships. Therefore, quality metrics may need to be expanded to recognize the breadth and duration of the survivorship experience. Clarifying definitions is important, as this may strongly affect the orientation of care and services. The fourth recommendation from the IOM report is that “quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive [4].”

Moving beyond survival, functional status, quality of life, and the personal cancer care experience emerge as critical and perhaps overlooked outcomes [31, 32]. Cancer survivors have more functional limitations due to their health than age-, gender-, and educational-attainment-matched controls, with 18% unable to work due to health problems (vs 10% for controls), 27% limited in the amount or kind of work that they can do because of health problems (vs 18%), 5% needing help in activities of daily living (vs 3%), and 11% needing help in independent activities of daily living (vs 7%) [34]. Survivors may have other long-term functional limitations.

A high proportion of cancer survivors have limitations in lower-body function, with 56% reporting difficulty in performing at least one of the following activities compared with only 27% of controls: walking one-quarter of a mile; walking up and down ten steps; standing for 2 h; stooping, crouching, or kneeling; and lifting 10 lb [35]. There are opportunities to provide the type of care needed to mitigate the impact of these functional limitations to enhance overall health.

Research is urgently needed to develop evidence-based approaches to improve outcomes for cancer survivors. In addition, however, we must determine what processes and structures of care will produce the highest quality outcomes given *current* scientific knowledge.

What Is Known About the Quality of Survivorship Care?

The ultimate objective of good quality cancer care is to achieve desired outcomes for survivors. This includes not only surviving the cancer but also living well. Thus, important outcomes for cancer survivors include not only overall and disease-free survival, but also functional status and quality of life, as well as their experience of care (satisfaction). Both structure and process of care, along with individual patient characteristics, contribute to outcomes (Fig. 2.1). The only way to improve the quality of outcomes is to improve the quality of the process and structure of care. Process is the set of activities that go on between patients and practitioners and includes both the technical and interpersonal quality of care. The structural dimension of health-care quality includes resources needed to provide medical care, such as the availability of imaging services or the professional education and competence of the providers.

Quality Indicators for the Processes of Survivorship Care

Quality of care can be measured across three dimensions: outcomes, process, and structure of care [36]. Measures of the process of care are referred to as “quality indicators.” Quality indicators take the form of an “if-then” statement, which is then represented as a ratio where the “if” is the denominator and the “then” is the numerator:

$$\text{Quality indicator} = \frac{\# \text{ patients who received the specified intervention}}{\# \text{ patients for whom the intervention is indicated} - \# \text{ patients reasonable to exempt from intervention}}$$

The numerator describes the care that should be provided. The denominator identifies the group of patients to whom the care should be provided. For example, when specifying a quality indicator for tamoxifen for breast cancer, it is necessary to determine which patients would be eligible, and in addition to identifying the cohort for whom tamoxifen is indicated, it may be desirable to exclude patients who

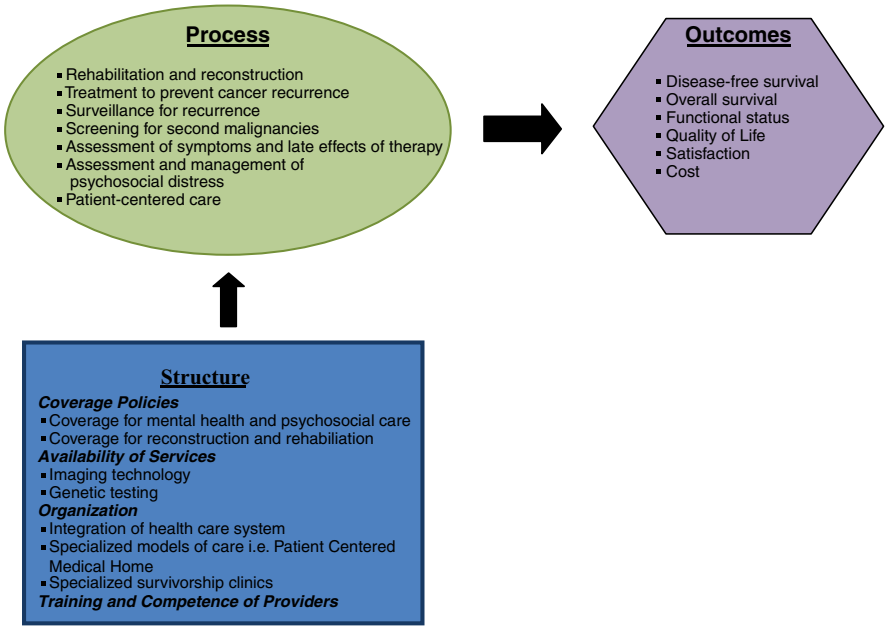


Fig. 2.1 Structure and processes of care that lead to desired outcomes for cancer survivors

refused. If a patient newly diagnosed with invasive breast cancer meets all of the criteria – is premenopausal, has estrogen receptor–positive or progesterone receptor–positive breast cancer, tumor size greater than 1 cm or involved axillary lymph nodes, and did not refuse tamoxifen – THEN the patient should receive tamoxifen. To operationalize this measure, the THEN statement becomes the numerator and all of the criteria in the IF statement need to be specified in the denominator.

$$\text{Quality indicator} = \frac{\begin{array}{l} \# \text{ eligible patients who received tamoxifen} \\ \# \text{ premenopausal women with ER or PR positive breast} \\ \text{cancer} > 1 \text{ cm or involved axillary lymph nodes} \\ - \# \text{ patients who refused tamoxifen} \end{array}}$$

Since the IOM called attention to the quality of cancer care in its 1999 report “Ensuring the Quality of Cancer Care [37],” a number of quality indicator sets have been developed to evaluate the quality of cancer care [38–43]. However, few of these quality indicators address posttreatment survivorship care and most focus on follow-up of people with a history of breast, colorectal, or prostate cancer, or melanoma. Of the four essential components of survivorship care described by the IOM (and discussed above), almost all of the indicators are focused on the second element (surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects) and most focus on detection of recurrence.

Of the quality indicators that address aspects of survivorship care (see Table 2.3), nine address surveillance (essential component 2) and the domains of prevention (essential component 1), consequences of cancer treatment (essential component 3), and

Table 2.3 Cancer survivorship quality indicators

Cancer type	Quality indicator	Indicator set	Level of evidence
All	Chemotherapy treatment summary completed; provided to patient; and communicated or provided to other practitioner(s) within 3 months of chemotherapy end.	QOPI	III
	Smoking cessation counseling recommended to cigarette smokers by second office visit.	QOPI	II
Breast cancer	If a patient with stage I–III breast cancer who initiates treatment with tamoxifen does not meet the following criteria for discontinuing tamoxifen: there is evidence of disease progression, then the patient should receive 5 years of tamoxifen 20 mg/day.	NICCQ	I
	If a patient with stage I–III breast cancer undergoes mastectomy, then prior to undergoing mastectomy the patient should be informed about the option of breast reconstruction after mastectomy.	NICCQ	III
	If a patient has been diagnosed with stage I–III breast cancer and has not had bilateral mastectomies, then the patient should have had a mammogram in the last 12 months.	NICCQ	I
	Women with a history of breast cancer should have yearly mammography.	QATOOL (RAND)	I
	Women diagnosed with breast cancer in the past 5 years should have a clinical breast exam in the past 6 months.	QATOOL (RAND)	III
	Women diagnosed with breast cancer more than 5 years ago should have a clinical breast exam in the past year.	QATOOL (RAND)	III
Colorectal cancer	If the patient has resection of a stage II or stage III colon rectal cancer, then the patient should be counseled about the need to have first degree relatives undergo colorectal cancer screening.	NICCQ	II
	Patients with stage I–III colorectal cancer, then he/she should receive colonoscopy or double contrast barium enema within 1 year of curative surgery if it did not occur within 12 months preoperatively.	QATOOL (RAND)	II
	Patients with stage I–III colorectal cancer should receive colonoscopy or double contrast barium enema within 3 years of curative surgery and every 5 years thereafter.	QATOOL (RAND)	I
Prostate cancer	Documentation/evidence of communication with patient's primary care physician or provision of continuing care.	RAND prostate	III
	At least two visits for follow-up by treating physician during the first posttreatment year.	RAND prostate	III
Melanoma	Patients with a personal history of cutaneous melanoma should receive a referral to a dermatologist for surveillance screening.	QATOOL (RAND)	III

QOPI Quality Oncology Practice Initiative, *NICCQ* National Initiative on Cancer Care Quality, *QATOOL* Quality Assessment Tool, *RAND* the RAND Corporation (Research And Development)

coordination between specialists and primary care providers (essential component 4) each have just one quality indicator. Additionally, only three are based on Level I evidence (adjuvant therapy with tamoxifen and screening for second cancers with mammography and colonoscopy).

Are Patients Receiving the Essential Components of Quality Survivorship Care?

Given the paucity of validated quality indicators, our knowledge of the quality of the process of care for cancer survivors is limited. Nevertheless, in recent years, a number of studies provide valuable insights on the quality of survivorship care.

Poor quality of care can result from too little care (underuse), too much care (overuse), or the wrong care (misuse). Most quality measurement has focused on underuse or misuse. Overuse of an intervention is an important indicator of poor quality when the potential for harm exceeds the potential benefit to patients. Overuse that does not have an adverse risk–benefit ratio may not be an indicator of poor quality care for the individual patient but may be undesirable because it results in inefficient resource allocation. Given the paucity of evidence-based quality indicators for survivorship care, our knowledge of the quality of survivorship care is somewhat limited. Nevertheless, the available data suggest that we are falling short on delivering the essential components of survivorship care proposed by the IOM.

Prevention of Recurrent and New Cancers, and of Other Late Effects

Unfortunately, few strategies currently exist for preventing recurrent or new primary cancers (beyond adjuvant therapy) and little is known about preventing late effects of treatment, although lifestyle factors, such as ceasing cigarette smoking, maintaining a healthy weight range, and regular exercise, may assist [23]. Nevertheless, the available data suggest that prevention efforts are lacking for those cancers where the evidence does demonstrate a benefit. Smoking cessation has been shown specifically to improve the outcomes of patients with lung cancer and head and neck cancer [44]. Additionally, smokers with a non-tobacco-related malignancy may be more receptive to counseling as their experience with cancer providing a “teachable moment [45].” Of course, stopping smoking has many other health benefits. In 2006 American Society of Clinical Oncology (ASCO) began integrating smoking-related measures into the ASCO Quality Oncology Practice Initiative (QOPI), a quality improvement program that enables oncology practices to assess their performance relative to their peers on a menu of quality measures. Among QOPI practices, smoking cessation counseling is offered to smokers only approximately 25% of the time [46]. Given that these are a self-selected group of

practices interested in quality improvement, this rate likely overestimates the rate of patients counseled about smoking prevention overall.

Most women with hormone receptor–positive breast cancer are prescribed hormonal therapy with tamoxifen or an aromatase inhibitor at the completion of the initial treatment not only to decrease their risk of distant recurrence but also to prevent local recurrence and second breast cancers. Although the rates of appropriate prescribing of adjuvant hormonal therapy are very high, the available data suggest that the quality of care to ensure that patients continue to receive this important therapy needs to be improved. In the NCCQ study, while 92% of women with hormone receptor breast cancers larger than 1 cm or positive lymph nodes received tamoxifen, only 74% of those who initiated therapy were still taking the medication when surveyed 4 years after diagnosis [47]. Other studies have reported even higher rates of discontinuation of tamoxifen ranging from 31% to 49% in women over 65 [48, 49]. Factors predicting non-adherence include older age and greater comorbidity but also having side effects from the medication [49], not being informed about side effects in advance of starting the medication, and having less support than needed [50], suggesting that adherence may improve with greater attention to the quality of survivorship care.

Surveillance for Cancer Spread, Recurrence, or Second Cancers; Assessment of Medical and Psychosocial Late Effects

There is strong evidence supporting the benefit of surveillance for new primaries for a number of cancers, including breast cancer, colorectal cancer, and consensus regarding the practice for others such as melanoma. While the data concerning the benefits of surveillance for local recurrence are less certain, the same modalities used to screen for a new primary would generally identify a local recurrence (e.g., mammogram and breast exam). Rates of adherence to mammography screening quality indicators are generally very high. In NCCQ, 94% of breast cancer survivors reported having received a mammogram in the prior year [47]. Rates of mammography are lower in older breast cancer survivors but still far exceed the mammography screening rates of women without a cancer history or who have other comorbid conditions (73% vs 59% vs 38%, respectively, for women enrolled in Medicare) [51]. Similarly, among colorectal cancer survivors, most appear to receive recommended colonoscopy screening with overall 74% having at least one colonoscopy within 3 years of diagnosis, with the proportion appropriately declining with age (83% of survivors 66–69 vs 47% of survivors 85 and older) and comorbidity (75% with no comorbid conditions and 69% with three or more comorbid conditions) [52]. Since patients with melanoma are at high risk for a second skin cancer, routine physical examination of the skin is recommended. In one study, more than 90% of Medicare patients diagnosed with melanoma in the US Surveillance, Epidemiology, and End Results (SEER) registry had a visit with a clinician for a skin examination within 2 years of their diagnosis [53]. Thus, while there may still be room for improvement, especially to address areas of health disparities, overall, at

least for common cancers where consensus exists on appropriate surveillance, the quality of care for detection of second cancers appears quite good.

Unfortunately, for only a handful of cancers does early identification of distant recurrence appear to result in improved outcomes. Randomized trials have found that for a number of cancers, including breast cancer and ovarian cancer, intensive monitoring for disease recurrence not only does not prolong survival but may worsen quality of life by adding to the number of months of palliative chemotherapy received [54, 55]. Because of this, clinical guidelines recommend against routine surveillance for cancer recurrence using tumor markers or imaging, except in those situations where early treatment has been shown to improve patient outcomes, such as resection of liver metastases in colorectal cancer or high-dose chemotherapy for lymphoma.

Given that until recently, the primary focus of care for cancer survivors has been on identifying relapses, it is perhaps not surprising that there appears to be extensive overuse of testing to detect cancer recurrences. Use of medical imaging in general has been increasing dramatically in recent years, with PET scanning becoming the most widely used imaging for patients with cancer in the USA [56–58]. Much of this increase reflects the overuse of these tests to detect cancer recurrences. In the US National Oncology PET Registry, 65% of PET scans were obtained for detection of recurrences despite the fact that guidelines do not recommend imaging surveillance for any of the nine malignancies that are included [58]. A recent study estimated that while cancer patients represented only 1% of the patients receiving imaging studies in Germany in 2000–2005, they received more than 10% of the effective dose of radiation delivered during that time [59]. The unfortunate irony is that this inappropriate surveillance for a cancer recurrence may place cancer survivors at increased risk for second primaries and other malignancies [60, 61].

Assessment of medical and psychosocial late effects has not been systematically studied, though appears suboptimal. As an illustration, Beaker and Luker studied the nature and content of hospital follow-up for women with early breast cancer [62]. Consultations were generally quite short (mean duration of 6 min) and focused on the detection of cancer recurrence. Unsurprisingly, few opportunities were available to meet supportive care needs. However, patients gained reassurance from these visits, as they were generally very optimistic.

Intervention for Consequences of Cancer and Its Treatment

Cancer and its treatments are associated with numerous physical and emotional consequences. While effective approaches to mitigate the effects of cancer treatment are sorely lacking, interventions do exist for a growing number. The consequences of often disfiguring cancer surgeries have long been recognized and several quality indicators speak to the need to address these issues. Although only 20–40% of women undergo breast reconstruction following mastectomy [63], over 80% report discussing reconstruction with their physicians [63, 64]. The NICCQ study included a quality indicator for breast reconstruction for women who have a mastectomy which recommends that prior to undergoing mastectomy the patient should be

informed about the option of breast reconstruction after mastectomy. In the NCCQ cohort there was widespread variation in adherence to this quality indicator with just over half of the patients receiving the specified care, but across cities this ranged from 39% to 65% [47]. Similarly, for patients with colorectal cancer who receive an ostomy during their primary surgery, reversal of the ostomy is critical for quality of life during survivorship when feasible and while data are limited, they suggest that this is often not performed after the patient completes their initial treatment. In the NCCQ study, 40% of patients with stage II rectal cancer and just 3% of patients with stage III rectal cancer had their ostomy reversed, although this included both patients who had abdominoperineal resections as well as low anterior resections, so some may not have been candidates for ostomy closure [65]. In contrast, a recent study of an intervention to increase the timeliness of ostomy closure by “setting a date” at the time of discharge from their primary surgery reported that 72% of patients undergoing low anterior resections had their ostomies closed [66]. These data suggest that there are widespread problems with the quality of survivorship care in the area of interventions to improve the consequences of cancer and its treatment, even when a well-accepted procedure is available and supported by guidelines.

The prevalence and time course of psychological distress in cancer survivors is not well described. Depression in survivors has been estimated to range from 10% to 58%, anxiety disorders reverse from 23% to 65%, and posttraumatic stress disorder from 0% to 32% [31]. A recent study found that while most patients did not report unmet supportive care needs following completion of their cancer treatment, 30% reported at least one unmet psychological need and for most the need persisted 6 months later [67]. While little is known about how or when to screen for distress [68] nor how best to intervene – currently available guidelines for the psychosocial care of patients with cancer do not address the posttreatment period [69] – this clearly is an area where attention to improving the process of care is needed in parallel to research to improve the tools and services to optimize psychological support for cancer survivors. Additionally, a variety of barriers to access psychosocial service exist, including the availability of providers, health-care coverage for services, as well as patient reluctance to discuss these issues. In the USA, even among patients who are insured, coverage of mental health services may be at lower reimbursement levels or included in behavioral health contracts, separate from medical coverage, posing additional barriers to access [70].

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Coordination Between Specialists and Primary Care Providers

Although data are limited, anecdotal reports and several small studies suggest significant problems in communication between cancer specialists and primary care providers providing ongoing care [29, 71, 72]. A recent study of 300 breast cancer survivors followed at an outpatient clinic of a university hospital found that only 28% thought that their oncologists and primary care providers communicated well [72].

While a majority of cancer survivors continue to follow-up with their oncologist for many years, the proportion of patients receiving their follow-up care solely from primary care physicians increases over time [73, 74]. Despite having to assume primary responsibility for survivorship care for a large proportion of cancer survivors, primary care physicians report uncertainty in their role in caring for survivors as well as lack of knowledge regarding late effects of cancer and its treatment [75, 76]. In a recent survey of primary care physicians, half of them reported feeling unprepared to evaluate and manage late effects of cancer treatment [7].

In 2005, in its seminal report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, the IOM recommended that patients completing primary cancer treatment “be provided with a comprehensive summary of their treatment together with a survivorship follow-up care plan written by the treating health care provider(s).” Although ASCO (available at <http://www.asco.org>) has developed templates and the Journey Forward, a collaborative effort of the UCLA Cancer Survivorship Center, NCCS, WellPoint, Inc, and Genentech (<http://www.JourneyForward.org>), has created tools for developing customized survivorship care plans, few oncologists have yet to make the survivorship care plans part of their routine practice. Among patients treated at oncology practices participating in ASCO’s Quality Oncology Practice Initiative (QOPI), in chart abstractions only 27% had received a treatment summary and had it communicated to the clinician providing continuing care within 3 months of completing chemotherapy in 2010. This is despite of it being a QOPI quality indicator since 2008. Given the importance placed upon this kind of communication by primary care physicians caring for survivors, it will be critical to develop strategies to overcome the barriers that are inhibiting the acceptance of treatment summaries and survivorship plans by oncologists. Expectations for survivorship care differ between patients and their physicians. A lack of clarity surrounding their respective roles may contribute to suboptimal levels of care [34].

Opportunities for Improvement

While available information on the quality of the process of care for cancer survivors must be considered very preliminary, it underscores the need to shift the focus of survivorship care from surveillance of disease recurrence, especially distant recurrence, to the other areas of survivorship care identified by the IOM including prevention of recurrence and new cancers; intervention for consequences of cancer and its treatment, including functional impairment, symptom burden, psychological distress; and coordination among specialists of several disciplines and primary care

providers. While the quality of care for surveillance for second cancers appears very good (although variation and potential disparities persist), there is substantial overuse of imaging and other tests for surveillance of distant recurrence that have not been shown to improve outcomes and may contribute to the risk of secondary malignancies. Gaps between existing care and ideal care are substantial for survivorship care, highlighting the urgent need of validated quality indicators both to monitor the quality of care and guide quality improvement interventions. Additionally, new models of care need to be explored and systematically studied as ways to deliver higher quality survivorship care more efficiently. Survivorship clinics run by nurse practitioners or physicians assistants and the Patient-Centered Medical Home are two different approaches discussed further in Chaps. 10 and 11.

Identifying Barriers to Optimal Care

There are several reasons why survivorship care may be inadequate. Firstly, there are insufficient means for identifying and addressing issues that are crucial for cancer survivors. Follow-up appointments, often occurring in busy clinics, are often too brief to adequately address the broad range of survivorship issues [62]. There is an urgent need for alternative models of posttreatment care [14, 29, 77]. Clinicians lack comprehensive assessment tools that could be administered in such an environment.

Secondly, responsibilities for follow-up are not clearly delineated between oncologists and primary care providers. Without an established system that includes accountability for each component of care, patients' needs are unmet, and there is a risk they will be lost to follow-up [4]. Even when these roles are delineated, primary care providers may lack training in survivorship issues and may not be able to rely on communication and advice from specialists [4].

Thirdly, although the ASCO is developing guidelines [78], there is currently insufficient evidence about the optimal frequency and content of follow-up appointments. Existing guidelines generally focus on detecting recurrence and second cancers and are not always easy for clinicians to access. Furthermore, evidence is lacking for self-care strategies that might improve management of treatment side effects [27]. To date, interventions have focused on limited health promotional strategies, particularly exercise programs and the reduction of physical side effects [24, 78]. More evidence-based support for psychosocial treatments would greatly improve their promotion and uptake. The IOM report recommended developing strategies to improve both physical and psychosocial outcomes [4].

Recommended Strategies to Promote Quality Survivorship Care

Much work is needed to improve survivorship care. Several priority areas and strategies have been identified to implement the above principles. Although discussed in greater detail elsewhere in this text, a few key points are described below.

Clinical Guidelines for Follow-up

There is a clear need for long-term continuous follow-up for cancer survivors. The IOM report revealed limited progress had been made to develop evidence-based guidance for providers of survivorship care. The IOM report recommended the development of “evidence-based clinical practice guidelines, assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment [4].” Guidelines should cover ongoing, repeat assessments and assist clinicians to manage the complex range of survivor issues; this will ensure that health changes related or unrelated to cancer can be detected when treatment or intervention is most likely to be effective [25].

Screening and Management of Psychosocial Issues

All cancer survivors require screening for distress and unmet needs. Mechanisms are also required that match these needs to interventions and other treatments. Psychosocial outcomes and efficient use of health resources may be enhanced by interventions tailored to the level of distress experienced [79]. Those involved in survivorship care should be encouraged to broaden discussions with survivors to include work, finances, and other social difficulties, and to develop appropriate referral pathways.

Education and Training

Survivorship issues should be part of the training of all health professionals, and be included in skills development for the current workforce. The IOM report recommended: “The National Cancer Institute, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality of life issues facing cancer survivors [4].” Improved awareness of the medical and psychosocial difficulties that can occur after cancer treatment will prompt appropriate assessment and intervention. This, combined with a system of increased accountability for follow-up, may give clinicians greater confidence to identify and manage survivor issues directly, rather than allowing patients to be lost in a system of referrals.

Survivorship Care Plans

Communication between health-care professionals is a serious concern in survivorship care. The IOM report recommended that all patients completing primary treatment be given a comprehensive care summary and follow-up plan. This should be

written by those who coordinated oncology treatment [4]. The summary should include all diagnosis and treatment information, plus details about any toxicities and complications experienced [12]. The care plan should recommend the frequency and duration of follow-up and a schedule for appointments, particularly if the survivor was being treated according to a shared care model. It should also provide strategies for dealing with current consequences of cancer and its treatments, health promotion strategies, and a list of support services.

A survivorship care plan is meant for the cancer survivor as well as their health-care providers. Structured care plans potentially will greatly improve communication between specialists and primary care providers; in the absence of such plans, health-care providers often rely on patient recall and understanding. There is widespread support for tailored care plans from survivors, nurses, and physicians, although more investigation is needed to determine the best ways to prepare and implement the plans [17, 80]. Ideally, care plans should be “living” documents that reflect current and projected circumstances.

Exploration and Assessment of Alternate Models of Care

It is critical that various models of follow-up be explored and rigorously evaluated. These models may include shared care models (specialist/primary care provider), specialist survivorship clinics (including long-term follow-up clinics) and nurse-led clinics [14, 29, 77]. Follow-up need not be face-to-face, but may be conducted by telephone or using the Internet. Self-management strategies should also be developed. These models should be studied to determine feasibility, acceptability, and effectiveness (including cost-effectiveness). Ideally, models should be broadly applicable to ensure that the greatest number of survivors is included. The IOM report has recommended that “The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Healthcare Research and Quality, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care [4].”

Conclusion

There is growing recognition of the need to improve the structure and process of care in order to optimize the outcomes of the expanding numbers of cancer survivors. Since much of the care of cancer survivors has heretofore focused on surveillance for recurrence, the development of evidence-based strategies for prevention, consequences of cancer treatment, and coordination of care has lagged, limiting the development of quality indicators in these areas. However, even as research is being conducted to develop evidence-based approaches to improve outcomes for cancer

Table 2.4 Priority areas to improve quality survivorship care that need immediate attention
Evidence-based strategies for detection and management of late-effects of cancer therapy
Evidence-based guidelines for comprehensive survivorship care across all cancer types
Evidence-based quality indicators for comprehensive survivorship care across all cancer types
Development of a comprehensive screening tool to tailor survivorship care to individual patient needs
Systematic review to identify best practices for delivering high quality survivorship care
Assessment of impact of imaging practices for surveillance on rates of second malignancies
Comparative effectiveness research to evaluate models for delivering survivorship care
Development of mechanisms to respond to identified gaps in high quality survivorship care
Development of quality improvement tools for survivorship care
Evaluation of coverage policies that may limit access to critical components of survivorship care (i.e. psychosocial services)

survivors, we must determine what processes and structures of care will produce the highest quality outcomes given *current* scientific knowledge. Key priority areas to improve quality survivorship care that need immediate attention include (Table 2.4):

- Evidence-based strategies for detection and management of late-effects of cancer therapy
- Evidence-based guidelines for comprehensive survivorship care across all cancer types
- Evidence-based quality indicators for comprehensive survivorship care across all cancer types
- Development of a comprehensive screening tool to tailor survivorship care to individual patient needs
- Systematic review to identify best practices for delivering high-quality survivorship care
- Assessment of impact of imaging practices for surveillance on rates of second malignancies
- Comparative effectiveness research to evaluate models for delivering survivorship care
- Development of mechanisms to respond to identified gaps in high-quality survivorship care
- Development of quality improvement tools for survivorship care
- Evaluation of coverage policies that may limit access to critical components of survivorship care (i.e., psychosocial services).

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