



# Models of care for early-stage breast cancer in Canada

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## ABSTRACT

There is growing evidence that follow-up for patients with early breast cancer (EBC) can be effectively carried out by the primary health care provider if a plan is in place. Here, we present data from a recent survey conducted in Ontario indicating that a shared-care model could work if communication between all health professionals involved in the care of EBC patients were to be improved. Patients and primary care providers benefit when the specialist provides written information about what their roles are and what to expect. Primary care providers need to have easy access to the specialist to discuss areas of concern. Patients also need to share responsibility for their care, ensuring that they attend follow-up visits on a regular basis and that they discuss areas of concern with their primary health care provider. A shared-care model has the potential to provide the best care for the least cost to the health system.

## KEY WORDS

Models of care, shared-care model, specialists, early breast cancer, referral

## 1. INTRODUCTION

Since the early 1990s, strategies for breast cancer treatment have evolved toward less extensive surgery, enhanced radiotherapy techniques, and improved systemic therapy, which, coupled with more effective screening programs, have led to significant improvements in breast cancer outcomes. Upon completion of initial treatment, patients with early breast cancer (EBC) transition into a period of “well follow-up,” during which they are monitored for recurrence detection, second primary breast cancer, and treatment-related toxicity. The 1998 Canadian Medical Association clinical practice guidelines for the care and treatment of breast cancer<sup>1</sup>, last updated in 2005, recommend follow-up after initial

treatment according to individual patient needs, with the responsibility for follow-up care allocated to a single physician, with the patient participating as fully as possible. The process and duration and the most responsible provider during this period vary, and there is no uniform Canada-wide care map specifying the provider who is to assume clinical responsibility for follow-up care, which is managed by the primary care physician in some jurisdictions and by specialists (medical oncologists, surgeons, radiation oncologists) in others.

Historically, specialist care has been the standard in many hospitals in Canada, but it has been suggested that primary care involvement in the follow-up of oncology patients is essential if optimal cancer care is to be achieved for all patients<sup>2</sup>. Consideration of this model is particularly relevant since cancer has surpassed cardiovascular disease as the main driver of mortality in much of the Western world. Furthermore, primary care physicians usually have the expertise and infrastructure in place to address the aspects of bone health, lipids, sexual health, and psychosocial issues, which often arise in the breast cancer survivor. Many breast cancer specialists also favour transferring the focus of care, on a risk-adjusted basis, to the primary care physician, provided that an appropriate oncology infrastructure is in place<sup>3</sup>.

A recent survey of Canadian physicians reported that primary care physicians were likely to assume exclusive responsibility for care after  $2.8 \pm 2.5$  years, although many were willing to take responsibility sooner if appropriate support were to be provided<sup>4</sup>. In a report from Ontario, it was found that follow-up care during the 5-year postoperative period in patients with EBC was provided in most cases (67%) by oncologists alone<sup>5</sup>, although 77% of family physicians believed it appropriate and expressed willingness to assume primary responsibility within 1 year of treatment<sup>6</sup>. More recent evidence gathered from across Canada suggested that 21% of family physicians were willing to assume immediate follow-up care of breast cancer patients after initial treatment<sup>4</sup>.

Standardization of well follow-up care across Canada for patients with EBC could facilitate provision of the best care for the least cost to the health system, without compromising the health status of individual patients. As increasing numbers of women with EBC survive longer and as adjuvant endocrine therapy continues for 5 or even 10 years, a survivorship care plan that addresses more than just surveillance and treatment for recurrence is needed. Such a plan should ideally integrate the individual's global health, late effects of adjuvant systemic therapy, compliance promotion, and management of adjuvant endocrine therapy side effects, and should address the psychosocial issues faced by EBC survivors.

Although there is no compelling evidence to support any particular frequency of clinical visits<sup>1</sup>, most Canadian cancer centres recommend visits every 6 months for 2–5 years, with annual visits thereafter. Here, we discuss the models of care that have been used, in Canada and in other countries, and we propose a model of care for follow-up after treatment of EBC in Canada with an emphasis not only on prevention and early detection of recurrence, but also on survivorship.

## 2. MODELS OF CARE IN EBC

Various models have been used to deliver well follow-up care for EBC patients, reflecting patient populations, geographic locations, institutional resources, and the availability of community-based care. They include specialist-based, primary-care-based, nurse-based and patient-initiated, and shared-care models. Specialist-based models have been the norm in many countries, but non-specialist models of care have been proposed as cost-effective alternatives in the follow-up of breast cancer patients and have demonstrated good patient satisfaction and outcomes<sup>7,8</sup>.

### 2.1 Specialist-Based Model

In recent years, with the development of breast cancer units in major hospitals, teams of specialists—usually comprising a medical oncologist, a radiation oncologist, and a surgical oncologist—have provided consultation, treatment, and follow-up care for EBC. Follow-up care consists of periodic routine visits, surveillance mammography, and monitoring for late effects of treatment. Although early detection of recurrence seems intuitively important, there is no evidence that detection of metastases through intensive testing provides a survival benefit over symptom-driven investigations<sup>9,10</sup>. A study to monitor recurrence of disease reported only 2 cases of locoregional recurrence detected among 104 patients through routine screening, whereas 7 cases were detected by clinical examination<sup>11</sup>. Median time to recurrence was 19 months for metastatic disease and 18 months for locoregional disease.

Specialist care generally focuses on surveillance for recurrence and on provision of specialized services to investigate symptoms of concern. However, care delivery in such a highly specialized environment often leaves little time to address other important psychosocial or health issues unrelated to the patient's breast cancer, which may also affect long-term health outcomes.

### 2.2 Primary-Care-Based Model

There is evidence demonstrating equivalent outcomes when follow-up care of EBC survivors is undertaken by primary care physicians, with the proviso that the primary care physician be interested in providing follow-up care, be actively involved, and have the time for appropriate follow-up. An 18-month study in the United Kingdom demonstrated that, compared with follow-up in a cancer centre, well follow-up of women with EBC by primary care physicians was not associated with an increase in time to diagnosis or in anxiety, nor with a deterioration in health-related quality of life<sup>12</sup>. In that study, frequency and length of visits were greater in primary care, and such visits were associated with lower costs to the health service<sup>13</sup>. A review of randomized controlled trials carried out between 1966 and 2004 confirmed that follow-up programs based on regular physical examination and yearly mammography alone were as effective as more intense approaches<sup>14</sup>. These core elements can readily be provided in the primary care setting to deliver long-term follow-up in patients with EBC. Indeed, a more recent randomized controlled trial conducted at 6 regional cancer centres in Ontario in women with EBC who were 9–15 months post diagnosis and who were followed for up to 5 years showed no significant difference between specialist and family physician care in relation to detection of recurrence-related serious clinical events and health-related quality of life<sup>15</sup>. The acceptability of family physician follow-up of breast cancer patients was assessed in that study, and 55% of the patients approached agreed to participate, suggesting that many patients are not opposed to receiving their care from the primary physician. However, physicians must be willing to provide such cancer care and to address the complex psychosocial and biomedical factors involved.

The primary care physician is well positioned to monitor adherence to therapy and to encourage compliance, and is also able to address psychosocial problems, which are prevalent in cancer patients<sup>16</sup>. A family physician-led model may also be ideal for managing specific health issues related to, or compounded by, previous or ongoing cancer therapy—for example, osteoporosis, dyslipidemia, cardiac health, and depression. If the primary care physician is to take on the responsibility of follow-up care for EBC survivors, appropriate education on

cancer recurrence, management of treatment-related toxicity, prevention, and risk-modifying strategies may be beneficial<sup>17</sup> in addition to facilitated communication with the oncologist<sup>18</sup>.

### 2.3 Nurse-Based Model

Oncology nurses are highly trained individuals who undertake a wide range of clinical activities and who can play a major role in follow-up care in oncology. Among patients with tumours of the central nervous system, nurse-based follow-up was found to be satisfactory and to decrease outpatient workload by 30%<sup>19</sup>. In a study of EBC patients with a low-to-moderate risk of recurrence, telephone follow-up by specialist nurses (consultation, with structured intervention and mammography) was as effective as traditional hospital follow-up (consultation, clinical examination, and mammography)<sup>20</sup>. Breast cancer nurse specialists may be particularly well-positioned to address the information and psychosocial needs of women with EBC, because those women are more likely to discuss their needs with a nurse than with a physician who is often perceived as being too busy to address such issues<sup>21,22</sup>. Some jurisdictions are incorporating advanced nurse practitioners who can act independently or in conjunction with a physician-led team as part of the clinical team providing oncology follow-up care<sup>23</sup>.

### 2.4 Patient-Initiated Model

In a study comparing average-risk EBC patients monitored through regular hospital clinic visits with patients monitored only at the time of mammography, patients expressed a preference for reducing rather than increasing follow-up visits<sup>24</sup>. Nevertheless, expectations by women of follow-up may vary. In a study comparing cancer-specific quality of life and psychological morbidity between women on standard clinic follow-up and those given written information on the signs and symptoms of recurrence, with instructions to report to a breast care nurse if they should encounter problems, more women in the standard-care group reported reassurance at being checked as an advantage; those in the patient-initiated group reported convenience as an advantage<sup>25</sup>. It has been suggested that by 1–2 years post treatment, some women with EBC may be sufficiently aware of the signs and symptoms of recurrence to embark on patient-initiated follow-up<sup>25</sup>. Although this care plan would help to reduce the burden on the cancer centres and primary care physicians alike, it does require validation in larger follow-up studies. Nevertheless, with appropriate education about signs and symptoms of local and systemic recurrence and with ongoing routine primary care, some women may be in a position to embark on a patient-initiated care model.

### 2.5 Shared-Care Models

There is some evidence suggesting that in certain jurisdictions, women who are monitored by both an oncologist and a primary care physician receive a better level of care. In a study of elderly women with EBC followed for 6 years or more in the United States, data from the Survival, Epidemiology and End Results database revealed that survivors who continued to see oncology specialists were more likely to receive appropriate surveillance mammography; by contrast, those who were monitored by primary care physicians were more likely to receive all other non-cancer-related preventive services. Those who saw both types of practitioners received more of both types of services<sup>26,27</sup>. Typically, the main focus of the oncologist is dealing with issues pertaining to the cancer, with less emphasis and time for other health concerns; the reverse might occur in the context of primary care, potentially leading to gaps in overall care<sup>28</sup>. Furthermore, diagnosis and treatment of cancer may have an impact on various aspects of health whose management primary care physicians are well positioned for<sup>29</sup>, but that might also benefit from support by a specialist. In a shared model of care being followed in some large centres in the United States, internists or allied health professionals are incorporated into the breast oncology practice and take on follow-up care when active treatment ends<sup>30</sup>. The cornerstone of shared care remains good communication and information transfer between the specialist and the primary care physician.

## 3. ATTITUDES OF PRIMARY CARE PHYSICIANS, ONCOLOGISTS, AND PATIENTS TOWARD EBC FOLLOW-UP

Although many specialists favour transferring care of EBC patients, on a risk-adjusted basis, to a primary care physician<sup>3</sup>, and although primary care physicians are willing to play a greater role in follow-up care<sup>4,31</sup>, consideration of the patient perspective is also important<sup>7</sup>.

Recently, we conducted 3 online surveys in Canada to determine the views of oncologists, primary care physicians, and patients on the well follow-up care of patients with EBC. In particular, the survey was designed to determine potential care gaps faced by primary care physicians in the management of patients with EBC, how oncologists communicate with primary care physicians, and how patients perceive their care after having been discharged to their primary care physician. Table 1 displays the findings of those surveys.

Most patients (87%) preferred to visit their specialist for routine follow-up, but only 57% felt strongly about this choice. More than half the respondents (57%) claimed to be equally comfortable with follow-up by either a specialist or a family physician,

TABLE 1 Key findings of recent online surveys

<i>Variable</i>	<i>Oncologists</i>	<i>Primary care physicians</i>	<i>Patients with EBC</i>
Respondents ( <i>n</i> )	47	275	54
Questions			
No difference in outcome whether routine follow-up is provided by oncologist or family physician	Agree 70%	Agree 51%	Disagree <sup>a</sup> 87% prefer to visit oncologist
Oncologists take the time to give instruction to primary care physicians	Agree 79%	Agree 63%	Agree 75%

<sup>a</sup> Among the same patient respondents, 44% claimed to prefer their family physician for follow-up care and 57% felt equally comfortable with follow-up by either an oncologist or their family physician. Almost all respondents (96%) felt that they knew where to go for immediate treatment related to their breast cancer.

with 44% expressing a preference for the family physician. Most patients (96%) felt that they knew where to go if they needed immediate treatment for any condition related to their breast cancer.

Most oncologists (70%) agreed that there was no difference in clinical outcome for routine follow-up performed by specialists or by primary care physicians, but only 51% of the primary care physicians agreed. Interestingly, although 79% of oncologists thought that they communicated well with the primary care physician and felt that they took the time to give proper instruction regarding follow-up care, only 63% of family physicians agreed. Those findings contrast with results from a previous Canadian survey of 183 oncology patients in New Brunswick, which revealed that 80% wanted counselling from their family physician, but that only 20% received it, and that 36% were not sure which physician was in charge of their follow-up care<sup>32</sup>. In that study, more patients (32%) were dissatisfied with the cancer care provided by the primary care physician; only 18% were not satisfied with specialist care. These contrasting findings may reflect diverse populations of oncology patient, regional or temporal differences in medical care, or other factors.

A range of patient attitudes to treatment have been identified in various studies. A survey carried out in 2001 in the Netherlands among women 2–4 years post treatment for EBC reported that more than half the patients preferred lifetime follow-up twice annually, and 86% preferred follow-up by a hospital-based physician<sup>33</sup>. Similarly, among 285 women with EBC in the United Kingdom, 85% preferred regular follow-up in a breast clinic, and 76% preferred regular breast clinic visits rather than family physician follow-up<sup>34</sup>. Among 300 EBC survivors in the United States, more than 70% were satisfied with general care, psychosocial support, and health promotion provided by their primary care physician, but only 50% perceived that their primary care physicians were knowledgeable about breast cancer follow-up

treatment, and only 28% felt that communication was good between their oncologist and their primary care physician<sup>35</sup>. Another survey carried out in the United Kingdom reported that patients were more satisfied with follow-up in general practice than in hospital outpatient departments<sup>36</sup>. Given the importance of the patient’s perspective in the area of follow-up care, a tailored approach has been proposed whereby patients decide whether they prefer specialist, primary, or alternative care<sup>7</sup>.

Discordant expectations with respect to their role in breast cancer follow-up have been identified for patients and primary care physicians alike. In some surveys, oncologists and primary care physicians both felt that they should carry substantial responsibility for follow-up care<sup>28,31</sup>. However, primary care physicians may not feel confident about all aspects of follow-up treatment. In an American survey, primary care physicians were comfortable addressing the potential side effects of treatment, but 51% reported not being comfortable in taking on responsibility for breast cancer surveillance, and only 41% were confident that they were following standard guidelines for surveillance<sup>37</sup>. In that survey, respondents highlighted the need for more communication from oncologists and especially for much more specific information regarding the surveillance plan. Similar gaps in communication and information transfer between the specialist and the primary care physician were identified in our survey. In Canada, where primary care physicians were willing to assume responsibility for care, support from the oncologist—such as a patient-specific letter from the specialist, printed guidelines, expedited routes of referral, and expedited access to investigations for suspected recurrence—was felt to be necessary<sup>4</sup>. A survey conducted in Ontario in 1993 found that primary care physicians were already using preventive and screening techniques for cancer in general in their practices, and that they were comfortable with most of their roles in supportive cancer care,

with the exception of conveying news of therapy failure<sup>38</sup>. However, significant dissatisfaction was expressed with certain aspects of the timing and content of the consultation letters received from the regional cancer centres.

Such observations suggest that primary care physicians are willing and able to take on follow-up treatment, but that timely, clear, and more structured communication and information transfer from oncologists is essential, as is readily available support when necessary. The complexity of cancer care and the emergence of multiple new adjuvant systemic therapies over the past decade pose a particular challenge for the communication of new information to primary care providers in an effective manner. Another challenge is the shortage in the number of primary care physicians available in many communities across Canada, which affects the entire spectrum of health care.

#### 4. CURRENT GUIDELINES FOR FOLLOW-UP OF EBC

Compliance with treatment guidelines for EBC has been associated with improved survival<sup>39</sup>, reduced economic costs<sup>40</sup>, and improvement in treatment practices<sup>41</sup>. Various guideline documents have been developed and undergo regular updates. The American Society for Clinical Oncology 2006 guidelines recommend a careful history and physical examination during hospital clinic visits every 3–6 months for the first 3 years, visits every 6–12 months for the next 2 years, and annual visits after 5 years<sup>42</sup>. The U.K. National Institute for Health and Clinical Excellence 2002 guideline is at the other end of the spectrum, recommending clinical follow-up limited to only 2 or 3 years<sup>43</sup>. The Canadian Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer, updated in 2005, take a middle ground regarding the frequency of visits and suggest that they should be tailored to individual patient needs, but should be provided indefinitely<sup>44</sup>. Guidelines also vary with respect to frequency of recommended tests. Both the American Society for Clinical Oncology and the Canadian guidelines recommend annual mammography, but the National Institute for Health and Clinical Excellence suggests that the yield of mammography is low and that local networks should decide on their own policy.

Although the guidelines published by the various groups disagree on the frequency of visits and testing and on the value of surveillance tests, there is general consensus that more intensive follow-up should be provided during the first 3–5 years after diagnosis and treatment, mirroring the period of highest risk of recurrence, with a transition to either reduced frequency of visits or discharge to the general practitioner thereafter<sup>45,46</sup>.

Responsibility for providing follow-up treatment varies by country. In the United States, the guideline

recommendation is that follow-up be carried out by a physician experienced in the surveillance of cancer patients and, in particular, in breast examinations<sup>42</sup>. In the United Kingdom, it is recommended that the family physician take on follow-up when clinic visits are discontinued and that a specialized breast care nurse be available for consultation indefinitely. In Canada, it is suggested that the responsibility for follow-up be allocated to a single physician and that the patient be fully informed of the arrangements for follow-up<sup>1,44</sup>.

Within Canada there are regional differences in the delivery of follow-up care for EBC. In Alberta, follow-up treatment is carried out largely by primary care physicians, and upon completion of primary treatment, patients who are not enrolled in clinical trials are discharged from oncology clinics to their family physician for ongoing follow-up and surveillance. The patient and the family physician both receive discharge letters outlining the recommended follow-up plan, signs of possible recurrence, and information on how to get back into the system if recurrence is confirmed or suspected<sup>23</sup>. In Quebec, a large proportion of well follow-up in EBC is carried out by surgeons and medical oncologists because 22.3% of adult women do not have a family physician<sup>47</sup> (reported from a study conducted in Laval, a northern suburb of Montreal, with a population of about 400,000). In Ontario, follow-up practice for EBC varies from one cancer centre to another, and no province has policies or guidelines on the topic.

#### 5. A NEW MODEL OF CARE FOR EBC

Historically, follow-up care for EBC has been focused on the detection and prevention of recurrence. With advances in adjuvant systemic therapy resulting in improved long-term outcomes, the focus of follow-up care for EBC has expanded to incorporate psychosocial care and maintenance of health-related quality of life such that not only survival but also survivorship takes on importance to reduce the impact of cancer on everyday life.

Because the efficacy of intensive testing in specialized clinics as a means of reducing recurrence rates has been questioned and because existing models of breast cancer follow-up care are being re-evaluated<sup>48</sup>, an opportunity exists to define new models of care. Ideally, cancer organizations should lead the development of a model for cancer survivors aimed at improving continuity and coordination of care and at providing a holistic approach to follow-up care in the long term. The Canadian Strategy for Cancer Control, a pan-Canadian organization that takes a comprehensive approach to cancer management, has reported that cancer care in Canada is not operating as an integrated whole or in a patient-focused manner<sup>49</sup>. This group found that many cancer patients feel isolated, sense that their care is fragmented, and are uncertain about

where to turn for help. It also reported that access to information, support, and services varies significantly with geographic location.

Although no difference in outcome has been detected between follow-up care led by primary care physicians and that led by specialists, our recent survey conducted with patients and practitioners in Ontario (Table 1) shows that only 51% of family physicians believe that patient outcomes would be unaffected if they assume follow-up care. Highlighting the importance of good communication and information transfer, 47% of family physicians surveyed felt that oncologists did not take the time to provide instructions for care. From the patient perspective, although 87% of respondents claimed to prefer follow-up by their oncologist, only 57% felt strongly about that choice, and 57% also claimed to feel equally comfortable with follow-up by either an oncologist or their family physician. These observations suggest that a shared-care model could work if communication between all the health professionals involved in the care of the EBC survivor were to be improved.

We view an integrated, shared-care approach—that is, specialists and other health care professionals are involved in the long-term follow-up care of EBC survivors, and patients are also encouraged to participate—as the ideal. Such a model must have the flexibility to adapt to patient preferences and also to local issues concerning human and other resources. The remainder of this section presents what we believe to be the cornerstones of a successful shared-care model.

### 5.1 Defining the Participants

Follow-up treatment in a shared-care model assigns equal responsibility to all the participants:

- Patient
- Primary care provider (family doctor, nurse practitioner)
- Specialists (surgeon, medical oncologist, radiation oncologist, general internist)

### 5.2 Defining the Roles and Responsibilities of the Participants

In a shared-care system, all the participants have a significant role to play, including the patient (Figure 1).

#### 5.2.1 Patient

Patients need to know that a plan is in place and that their family physician is well equipped to deal with their long-term follow-up care. They should also take on the responsibility for regular breast self-examination. We recommend that patients be provided with a letter outlining standard follow-up recommendations (Table 11). Furthermore, patients should be encouraged to take responsibility to seek

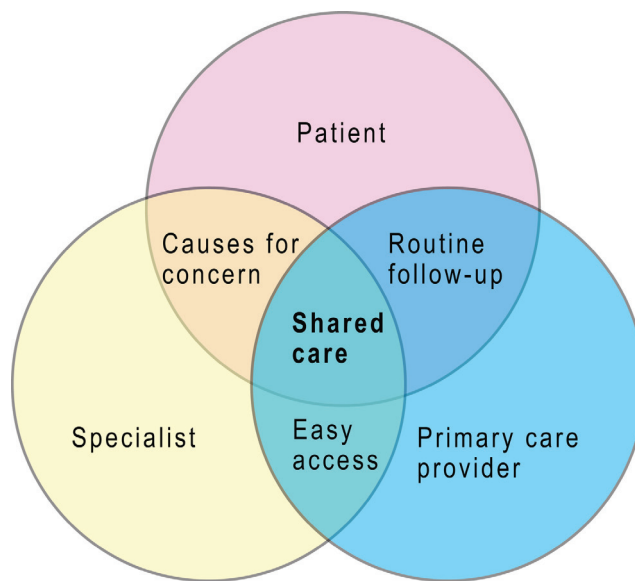


FIGURE 1 Participant responsibilities in a shared care model.

and preserve “wellness” through maintenance of a healthy weight (that is, avoidance of obesity), reduced alcohol consumption (fewer than 3 drinks per week or less than half a drink daily), intake of appropriate amounts of vitamin D (2000 IU for healthy postmenopausal women), and participation in regular physical activity<sup>50</sup>. Sedentary behaviour and decreased exercise levels have recently been shown to be associated with de-conditioning and poor symptom control after cancer diagnosis<sup>51</sup>.

#### 5.2.2 Primary Care Provider

The primary care provider should receive a letter from the oncologist outlining standard follow-up recommendations (Table 111). The primary care provider should track follow-up visits, be they at 6- or 12-month intervals, and should send reminders to patients when their appointments are due, as occurs in specialist clinics. Suspicious findings in the breast detected through breast examination or mammography should be referred to the surgeon for tissue diagnosis and not to the medical or radiation oncologist. Primary care providers also need to be provided with direction, as needed, for appropriate investigations that should be considered for persistent systemic symptoms without a clear cause—for example, a bone scan for persistent, unexplained bone-related pain, or chest radiography or computed tomography for persistent respiratory symptoms such as shortness of breath or persistent cough. Patients on long-term oral endocrine therapy need to be monitored for adherence to therapy. Those on aromatase inhibitors need to be counselled on adequate vitamin D and calcium intake and need to undergo bone mineral density surveillance at 1- to 2-year intervals. Any problematic side effects of therapy should be discussed with the oncologist.

TABLE II Key information for patients with regard to follow-up treatment

Advise patients that their care is being transferred from the cancer centre back to the primary care provider.

Inform patients that it is their responsibility to contact their primary care provider and arrange for their own follow-up visits.

Provide patients with these standard follow-up treatment recommendations:

Examination by the primary care provider should be performed every 6–12 months for 2 years based on risk category as defined by the specialist, and then annually.

Annual mammography (at any accredited mammography facility) should be performed.

Breast and axilla (armpit) self-examination (both sides) should be performed each month.

In the absence of symptoms about which the primary care provider has concerns, regular chest radiography, bone scans, ultrasonography of the abdomen, or lab tests are *not* recommended as routine follow-up.

Patients on tamoxifen therapy should contact their primary health provider immediately if abnormal vaginal bleeding or leg swelling occurs.

Patients on aromatase inhibitors should be aware of the associated potential for bone thinning (osteopenia or osteoporosis) that increases the risk of fracture and of their need for regular bone mineral density testing.

Women who have gone through menopause should exercise regularly and take both calcium and vitamin D to help maintain bone strength.

Additional medications (such as bisphosphonates) may be prescribed if thin bones or risk for bone fracture (osteopenia or osteoporosis) is diagnosed.

Any new breast lumps, persistent bone pain, shortness of breath, arm or leg swelling, or abnormal vaginal bleeding should be reported to the primary care provider.

### 5.2.3 Specialists

Each specialist has to define short- and long-term treatment plans for individual patients. This is particularly important for patients on long-term adjuvant endocrine therapy for EBC, such that the plan is clearly stated in the discharge letter as

- a plan for 5 years of adjuvant endocrine therapy, and then cessation; or
- a plan for a switch to an aromatase inhibitor after 2–3 years of tamoxifen; or
- a plan for a switch to an aromatase inhibitor after 5 years of tamoxifen.

The oncologist should also state possible alternatives in therapy; in some cases, it may be appropriate or necessary for the patient to be referred back to the oncologist for renewed discussion of the treatment plan, particularly in light of unmanageable toxicity. Written information should be provided both to the primary care provider and to the patient as summarized in Tables II and III.

The oncologist should be able to provide cancer patients with access to psychosocial resources or contacts if required, and also access to genetic counselling if hereditary breast cancer is known or suspected.

### 5.3 Distilling the Core Elements of Follow-Up

The core elements of follow-up are straightforward. In short:

- Regular history and physical exam
- Annual surveillance mammography

- Surveillance of bone mineral density for patients on aromatase inhibitors
- Other tests only on a symptom-driven basis

Any cause for concern on the part of the primary care provider should initiate a discussion with or referral to the specialist (or both) as outlined in Table III.

### 5.4 Communication and Information Transfer

The success of a shared-care system is based on clear and facilitated channels of communication and information transfer between the specialist or specialists, the patient, and the primary care provider<sup>52</sup>. The primary care provider should have telephone access to specialists, and the primary care provider and the patient should both have reassurance of a swift return to specialist care in the event of a problem. Most importantly, the primary care provider and the specialist should have a mutually agreed-upon and specific back-up plan or course of action to follow in the event of a problem.

## 6. SUMMARY

There is growing evidence that follow-up treatment can be effectively carried out by the primary health care provider, if a plan is in place. Our recent survey in Ontario indicates that a shared-care model could work if communication between specialists and all health professionals involved in the care of the EBC survivor were to be improved. Patients and primary care providers both need to be provided with written information from the specialist about what their roles

TABLE III Key information for primary care provider with regard to follow-up treatment

Inform the primary care provider that the patient is being discharged from the cancer centre back to their care for continued follow-up.

Advise the primary care provider to schedule follow-up visits every 6–12 months based on the risk category and time since diagnosis.

Recommend the following schedule, consistent with Canadian Medical Association guidelines:

Clinical examination should be conducted every 6–12 months for 2 years based on risk category as defined by the specialist, and then annually.

Clinical examination should consist of examination of the breasts, chest wall, supraclavicular and axillary lymph nodes, auscultation of the chest, and palpation of the liver.

Annual diagnostic mammography should be performed.

Any problems in the breast should be referred to the surgeon and not to the oncologist.

Appropriate imaging should be booked for persistent unexplained systemic symptoms without a clear cause.

Routine investigations (for example, bone scans, ultrasonography of the abdomen, chest radiography, laboratory tests) are *not* recommended for asymptomatic patients.

For any patient with a history of breast cancer, the use of estrogen, raloxifene, or any hormone replacement therapy is contraindicated.

Patients receiving tamoxifen are at a slightly increased risk of deep vein thrombosis and endometrial cancer; these patients should be referred to a gynaecologist if they report abnormal vaginal bleeding.

Patients receiving aromatase inhibitors are at risk for developing osteopenia or osteoporosis (or both). Baseline and annual bone density testing (by dual-emission X-ray absorptiometry) should be performed every 1–2 years and treated according to clinical practice guidelines.

Optimized bone health should be promoted through standard recommendations—that is, daily calcium and vitamin D supplements, and regular physical activity. Risk factor modification should also apply.

If the patient is having any of the following signs or symptoms potentially indicative of local recurrence or metastatic disease, appropriate investigations should be scheduled:

<i>Sign or symptom</i>	<i>Investigation</i>
New mass in breast	Mammography (possibly with biopsy); refer to surgeon
Rash or nodule on chest wall	Refer to surgeon
Palpable lymphadenopathy	Refer to surgeon
New persistent bone pain	Bone scan and plain films of affected site or sites
New persistent cough or dyspnea	Chest radiography
Hepatomegaly or pain in the right upper quadrant	Ultrasonography or computed tomography (or both) of abdomen, plus liver enzymes
Other symptoms or findings	Depends on the specific problem; refer to oncologist if symptoms persist

*Urgent* referral to a specialist is recommended for *any* of the following symptoms:

<i>Sign or symptom</i>	<i>Urgent referral to</i>
Back pain with limb weakness, change in sensation, change in reflexes, or loss of bowel or bladder control	Radiation oncologist for possible spinal cord compression
New persistent headache (especially with visual changes, nausea, or seizures)	Radiation oncologist for possible brain metastases
Altered level of consciousness, nausea, vomiting, or pain associated with hypercalcemia	Medical oncologist for management of hypercalcemia



are and what to expect. Primary care providers need to have easy access to specialists to discuss areas of concern and referrals to specialists as appropriate. Patients also need to assume responsibility for their care, ensuring that they attend follow-up visits on a regular basis and that they discuss areas of concern with their primary health care provider. A shared-care model has the potential to provide excellent care at less cost to the health care system.

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