Survivorship Model of Care

Development and implementation of a nurse practitioner–led intervention for patients with breast cancer

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BACKGROUND: Despite a call for action to improve survivorship care, no optimal model of care exists.

OBJECTIVES: To develop and evaluate the feasibility of a nurse practitioner (NP)–led model of care for survivorship visits after initial therapy.

METHODS: Patients received an NP-led survivorship bridge visit (NPSBV) following treatment for early-stage breast cancer. A cross-sectional survey was used to evaluate responses to the NPSBV and patient satisfaction with care. Satisfaction with usual care was evaluated in a comparison of patient groups. Differences were assessed with a chi-square test or Fisher’s exact test.

FINDINGS: Of 166 surveys, 118 were returned. The NPSBV met feasibility with a high attendance rate and had high acceptability and satisfaction rates. NPSBV patients were more likely to report that their team always cared as much as they did about their health compared to controls. Most patients would recommend the NPSBV to others.

BACKGROUND:
IN 2006, HEWITT, GREENFIELD, AND STOVALL published From Cancer Patient to Cancer Survivor: Lost in Transition, a report that describes cancer survivorship care and the Institute of Medicine’s recommendations. Since then, survivorship clinics and interventions have been established throughout the country with various models and levels of success. Despite a growing body of literature on this topic, the optimal delivery model to address the healthcare needs of cancer survivors has yet to be established.

Barriers to survivorship care implementation are well documented and include challenges with staffing, clinician time, and clinic resources (Birken, Mayer, & Weiner, 2013; Mayer, Birken, Check, & Chen, 2015). Hewitt et al. (2006) also recommended that every patient receive a survivorship care plan (SCP) detailing follow-up care, a surveillance plan, and general health recommendations. However, other literature reveals that SCP adoption in oncology clinics is highly variable, and insufficient evidence suggests that SCPs improve outcomes for patient (Mayer et al., 2014; Salz et al., 2014).

Background
About 15.5 million cancer survivors live in the United States today, and more than 3.5 million of them are breast cancer survivors (American Cancer Society, 2016). The potential needs of breast cancer survivors and the long-term sequelae following treatment are well documented and include depression, anxiety, fatigue, peripheral neuropathy, body image concerns and complications postreconstruction, bone health, menopausal symptoms, cognitive changes, sexuality issues, and lymphedema (Bluethmann et al., 2015; Gopie et al., 2013; Lester et al., 2015; Partridge, 2013; Pauwels, Charlier, De Bourdeaudhuij, Lechner, & Van Hoof, 2013; Soo & Sherman, 2015). Treatments exist for many of these issues, yet many cancer survivors report not connecting with the necessary providers to address their concerns (Todd, Feuerstein, Gehrke, Hydeman, & Beaupin, 2015). A growing public health challenge is appropriately screening for these issues among patients with breast cancer, identifying patients in need, and efficiently directing them to appropriate resources. Collectively, these findings suggest a need to develop clinical models that...
systematically ensure that patients’ needs are identified and addressed following initial breast cancer treatment.

Approaches to adult cancer survivorship care vary by setting and disease type. The three models for comprehensive survivorship care that have been identified in academic institutions are consultative clinics, embedded nurse practitioner (NP)–led survivorship clinics, and specialized multidisciplinary survivor programs (McCabe & Jacobs, 2012; Oeffinger & McCabe, 2006). The consultative clinic and multidisciplinary survivorship clinic models may address survivors’ needs, but they have drawbacks. In addition to regular follow-up care, they require patients to return for another visit at a different clinic. Patients’ primary oncology team, who knows their case well, can prepare for survivorship care visits and create SCPs relatively quickly, whereas new providers, as seen in the consultative and multidisciplinary models, may require more time to do the same tasks (Salz et al., 2014). Because SCPs were deemed sufficiently valuable and cost-effective, they were advised for adoption in advance of strong evidence for their effectiveness (Hewitt et al., 2006). Subsequent research has shown that, if developed by providers who are unfamiliar with the patient, SCPs can be inefficient and ineffective (Grunfeld et al., 2011; Nicolaije et al., 2015).

Consultative and multidisciplinary care clinics also add to the complexity of care and communication among providers by introducing new providers to the patient and primary care team, which is not aligned with the goal to improve communication among patients’ oncology and primary care teams (Hewitt et al., 2006). In addition, a successful survivorship care model should provide efficient, streamlined, and sustainable survivorship care within a resource-limited healthcare system (American Society of Clinical Oncology, 2008).

The current authors sought to develop a model of survivorship care built on the existing relationship between the patient and oncology team and the subspecialized knowledge base of the breast cancer NPs. A multidisciplinary team created an NP-led survivorship bridge visit (NPSBV) to provide the survivorship care recommended by the Institute of Medicine and the American Society of Clinical Oncology. The goals of the NPSBV were to provide patients with an individualized SCP, including treatment summaries, a five-year follow-up and disease recurrence surveillance plan, and information regarding quality of life and wellness concerns of adjuvant breast cancer survivors, in a face-to-face visit with a medical oncology NP. The purpose of this study was to evaluate the feasibility of and patient satisfaction with the NPSBV. A secondary aim was to evaluate satisfaction with overall care between the intervention group and a group of patients presenting for regular follow-up as a nonmatched convenience sample control population.

Methods
A descriptive, cross-sectional comparison group design was used to compare women’s satisfaction with the NPSBV. The interven-

“The nurse practitioner–led survivorship bridge visit can be tailored to meet individual practice or disease group needs.”

tion group received the NPSBV, and the control group received usual care.

Setting and Sample
This study was conducted at Massachusetts General Hospital, a large academic hospital with a subspecialized breast oncology clinic in Boston. All patients diagnosed with early-stage breast cancer (stage I–III) who completed active therapy (surgery with or without chemotherapy, with or without radiation) within about two to six months were eligible to participate in the study. Patients with metastatic breast cancer were excluded because of their different needs and issues (Mayer, Green, et al., 2015).

Patients who were eligible for the NPSBV were identified and recruited by their physicians or NPs. To ensure the NPSBVs were occurred at the end of the treatment phase, the appointments were often scheduled six months or more prior to patients completing treatment, and rescheduling was allowed, as needed, to align with patients’ treatment schedules and needs. The control arm of the study included patients who were not scheduled for a NPSBV prior to six months after treatment completion but who otherwise met eligibility criteria.

Prior to commencement of the study, Massachusetts General Hospital’s Institutional Review Board reviewed and approved the study. The institutional review board waived the need to obtain consent because the study was low risk, evaluating the satisfaction of a program of care. The privacy and confidentiality of all participants was assured and all data were coded, deidentified, and kept in a locked cabinet.

Intervention
The NPSBV consisted of a 30- to 45-minute, face-to-face encounter between the patient and oncology NP who cared for him or her during active therapy. A multidisciplinary team, including medical and surgical oncology NPs, surgeons, medical
FIGURE 1.
SURVIVORSHIP CARE PLAN

<table>
<thead>
<tr>
<th>PATIENT NAME:</th>
<th>DATE:</th>
<th>DIAGNOSIS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEDICAL ONCOLOGIST:</td>
<td>PHONE:</td>
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</tr>
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<td>SURGICAL ONCOLOGIST:</td>
<td>PHONE:</td>
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</tr>
<tr>
<td>RADIATION ONCOLOGIST:</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>FOLLOW-UP CARE OR TEST</th>
<th>RECOMMENDATION</th>
<th>PROVIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical and physical history</td>
<td>Every six months for the first five years, then once per year</td>
<td>Medical, surgical, or radiation oncologist, or nurse practitioner and/or primary care provider</td>
</tr>
<tr>
<td>Mammography</td>
<td>Once per year</td>
<td>–</td>
</tr>
<tr>
<td>Bone density</td>
<td>Every two years</td>
<td>Medical oncologist or primary care provider</td>
</tr>
<tr>
<td>Pelvic examination</td>
<td>–</td>
<td>Gynecologist or primary care provider</td>
</tr>
<tr>
<td>Coordination of care</td>
<td>Maintain a healthy lifestyle and see your primary care provider for routine maintenance.</td>
<td>Primary care provider</td>
</tr>
</tbody>
</table>

*Note.* Tests will be ordered as appropriate for your individual care.

SUGGESTIONS FOR MOVING FORWARD
- Continue to follow up with your oncology team to monitor risk for breast cancer recurrence.
- Report any persistent symptoms—such as new lumps, bone pain, pain in a specific area of the breast, chest pain, shortness of breath, any difficulty breathing, new swelling in the breast or arm, unexplained weight loss, abdominal pain, persistent headaches, or other new or concerning symptoms—to your team.
- The following tests are not recommended for routine breast cancer follow up: breast magnetic resonance imaging, positron-emission tomography with fluorodeoxyglucose, computerized tomography, blood counts or chemistry studies, chest x-rays, bone scans, and tumor markers tests (CEA, CA 15-3, CA 27, 29, CA 125). Your provider will order these tests if they are determined to be right for you.
- Tell your team if you have a family history of cancer or if a member of the family is newly diagnosed with cancer, as they may refer you for genetic counseling.

LIFESTYLE RECOMMENDATIONS
Lifestyle changes have been shown to decrease breast cancer risk, even in high-risk women. The following are steps you can take to lower your risk:
- **Limit alcohol.** The more alcohol you drink, the greater your risk for developing breast cancer. If you choose to drink alcohol—including beer, wine, and liquor—limit yourself to no more than one drink per day.
- **Do not smoke.** Accumulating evidence suggests a link between smoking and breast cancer risk, particularly in premenopausal women. In addition, not smoking is one of the best things you can do for your overall health.
- **Control weight.** Being overweight or obese increases your risk for breast cancer, particularly if obesity occurs later in life, such as after menopause.
- **Stay physically active.** Being physically active is one of the best things you can do for your health. It helps you maintain a healthy weight and lowers your risk for heart disease, stroke, and diabetes. Some studies suggest it may also increase breast cancer survival and lower risk for recurrence.

Please discuss any hormonal therapy or birth control methods with your oncologist.

EMOTIONAL AND SPIRITUAL HEALTH
For many patients, the end of treatment is a time of mixed feelings. Most people are relieved to be finished with treatment, but many also experience sadness and worry. Share your emotional concerns with your medical team.
- Oncology social workers are licensed counselors and members of your medical team. They are available to you and your family to help you adjust to life after cancer. For more information about connecting with a social worker, ask your treatment team.
- Oncology chaplains are familiar with the unique needs of those recovering from cancer.

PHYSICAL REHABILITATION
Some physical impairments from cancer therapies can be addressed with cancer rehabilitation treatment. Your team can refer you to services, such as physical therapy, occupational therapy, nutritional counseling, and services at the sexual health clinic. Please ask your team if you have any concerns.

OTHER RESOURCES
Cancer centers should list their preferred resources in this section.
oncologists, radiation oncologists, cancer center administrators, oncology social workers, and physical therapists, was formed to create the content for the NPSBV. The team met every other week for six months to conduct a landscape assessment of existing survivorship programs at comparable cancer centers and to review national guidelines to develop the content and format for the intervention.

SURVIVORSHIP CARE PLAN DEVELOPMENT
The multidisciplinary team created a one-page handout to serve as the SCP, supplementing the conversation between the NP and patient. This is consistent with the literature, which suggests that patients want a concise, written SCP but that informational handouts alone cannot fulfill their needs for survivorship information (Marbach & Griffie, 2011; Mayer, Gerstel, Leak, & Smith, 2012). The SCP aligns with format recommendations by the American Society of Clinical Oncology and included the following information: contact information of the oncology care team; review of diagnosis and treatments; office visit and imaging follow-up plan; discussion of recurrence risk; list of concerning symptoms and when to call; information regarding genetic counseling; lifestyle and wellness recommendations; information on spirituality, sexual health, and physical rehabilitation; and community resources for breast cancer survivors (Mayer et al., 2014).

The timeline for the visit was about two to six months after completion of active therapy, consistent with the literature documenting that cancer survivors’ distress is highest during the first six months post-treatment (Lester et al., 2015) and that they prefer to receive SCPs close to or soon after completing treatment (Marbach & Griffie, 2013; Mayer et al., 2012). A SCP template was created for patients diagnosed with ductal carcinoma in situ, and one was created for patients diagnosed with invasive disease. Both formats were incorporated into the clinic’s electronic health record system. Prior to implementation, the one-page SCP was reviewed and revised by the entire multidisciplinary team and by the patient and family advisory council.

THE NURSE PRACTITIONER–LED SURVIVORSHIP BRIDGE VISIT
The NPSBV was scheduled as a stand-alone visit at a time convenient for the patient or immediately following a routine follow-up visit with an oncologist. During this intervention, the NP and patient discussed topics on the SCP. They worked together to review and tailor the SCP to meet the patient’s needs, focusing discussion on the issues most important to him or her. See Figure 1 for an illustration of the SCP.

TABLE 1.
SAMPLE CHARACTERISTICS

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<tr>
<th>CHARACTERISTIC</th>
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<th>CONTROL (N = 45)</th>
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<td>55–64</td>
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<td>65–74</td>
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Continued on the next page
to attend a one-hour training session to review the goals and content of the NPSBV and the format of the SCP. The NPs were provided with a script to guide the visit, including answers to common questions and concerns. Prior to conducting an independent NPSBV, the NPs observed the leader of the current study lead an NPSBV and then practiced on a colleague. The NPs also attended quarterly refresher sessions to discuss any logistical or content concerns with the NPSBV. The principal investigator was available throughout the study to address any questions or concerns.

Instruments
Patients participating in the NPSBV received a cross-sectional, self-administered paper survey that took about five minutes to complete. The survey asked for demographic information and evaluated their satisfaction with overall cancer care and the NPSBV. The controls received the same survey about overall cancer care and demographics but did not answer questions related to the NPSBV. The survey questions for both instruments were adapted from the Cancer Adult Ambulatory Consumer Assessment of Healthcare Providers and Systems instrument (Agency for Healthcare Research and Quality, 2010). This survey has established psychometrics across care settings and is used extensively in ambulatory settings to evaluate patient experience and satisfaction with care (Dyer, Sorra, Smith, Cleary, & Hays, 2013).

Data Collection and Analysis
The control and intervention surveys were anonymous and contained no personal identifiers. The NP conducting the NPSBV administered the survey following the visit to the intervention patients. The control patients received the survey by mail. Both groups received a self-addressed stamped envelope with which to return the survey.

Throughout the study, a log was kept of all patients who received the intervention survey or control survey to track the response rate. The log and survey data for the control and intervention group were entered into a REDCap database by two members of the research team to ensure accuracy.

The primary endpoint of this study was the feasibility and patient satisfaction with the NPSBV and overall care of the intervention patients. Satisfaction with overall care alone was evaluated in the control group. Feasibility was defined as a greater than 75% attendance rate. A secondary aim was to determine if any improvement or detriment to patient satisfaction occurred because of the intervention compared to patients who attended a routine breast cancer follow-up. Results were descriptive with differences between groups assessed with a chi-square test or Fisher’s exact test and a two-tailed p value of 0.05.

Results
One hundred twenty-two patients were scheduled for a NPSBV as a supplement to routine care, and all but one attended the visit. One hundred eighteen of 166 surveys evaluating satisfaction with care in both groups were returned for a 71% response rate. Among the intervention patients, 73 of 109 surveys assessing the impact of this visit were returned (67% response rate). Among the control patients, 45 of 57 surveys assessing satisfaction with overall care were returned (79% response rate). Forty-seven of intervention patients were aged 55 or older, and most were White. Sixty-four had a college or postgraduate education, and 43 reported an annual income of $75,000 or more. Half of the controls were aged 55 or older, and most were White. Thirty of the usual care controls reported a college or postgraduate education, and 31 reported an annual income of $75,000 or more. The only significant difference found between groups using Fisher’s exact test was for race (p = 0.012); all other differences were nonsignificant. See Table 1 for demographic details.

Overall satisfaction with care was rated on a scale from 1 (never) to 4 (always) and was high in both groups. One hundred twelve participants reported that their providers always had respect for what they had to say, 110 reported that their providers always spent enough time with them, and 110 reported that they always trusted their providers with their medical care. A significant difference existed between groups when asked if they felt...
their care team cared as much as they did about their health, with 66 intervention patients responding “always” compared to only 36 control patients (p = 0.006). All other between-group differences were nonsignificant.

Feasibility of the NPSBV was demonstrated with a 99% attendance rate and high acceptability and satisfaction rates. Sixty-eight reported that it provided easy-to-understand information. Sixty-eight participants reported that the NPSBV helped explain the follow-up plan for treatment, 70 reported that it addressed emotional/spiritual concerns, 71 reported that it provided helpful information on lifestyle/wellness, and 71 reported that they would recommend the NPSBV to other patients. However, 3 patients felt that their emotional/spiritual needs were not met by the NPSBV, and 10 felt that their emotional/spiritual needs were only somewhat met. In addition, 13 participants felt that the NPSBV only somewhat resolved the concerns they had regarding breast cancer survivorship care prior to the intervention.

Discussion
The needs of breast cancer survivors are well documented, but determining the most effective and efficient way to meet these needs following initial therapy remains a challenge. This study demonstrates the feasibility and high patient satisfaction associated with the NPSBV, an embedded survivorship care model for patients with breast cancer. However, it has been noted that non-White patients are more likely to be dissatisfied with care (Barr, 2004; Malat, 2001; Pinder, Ferguson, & Møller, 2016). The higher percentage of Black or African American patients in the control group could have contributed to the differences between groups.

The NPSBV model used existing personnel and clinic resources and capitalized on the subspecialized knowledge base of the breast cancer NPs and their existing relationship with patients. It is efficient and promotes care continuity, which aligns with the call for a patient-centered approach to survivorship care (Institute of Medicine, 2001; Nekhlyudov, Levit, Hurria, & Ganz, 2014). As reported by Oeffinger and McCabe (2006), NP-led survivorship care is “relatively low cost in terms of personnel and dollars,” and “appointment time slots for the oncologist are opened for the care of newly diagnosed patients or those in active treatment” (p. 5122). The NPSBV model is flexible and pragmatic, allowing the NPSBV to accommodate the individual patient and the needs of the clinic.

Intervention Feasibility
The NPSBV can be implemented using a medical oncology practice’s current resources, as this study reveals. The NPSBV uses a brief, one-page SCP, which can be filled out quickly by NPs because of the format and their knowledge of the patients. The SCP is concise but informative and can be used within an electronic health record system, and the NPSBV can be tailored to meet individual practice or disease group needs and can be edited to reflect national guidelines as they evolve.

Limitations
The patient population at Massachusetts General Hospital is comprised of predominantly White, English-speaking, well-educated, middle-class women. The sample size was small and the survey brief, limiting the authors’ ability to infer causality. Patients in both groups were highly satisfied with their care, which may reflect selection bias in study participation and referral to the NPSBV. The authors did not collect data on disease stage for comparison with patient satisfaction (i.e., ductal carcinoma in situ versus invasive disease) or the number of patients offered the NPSBV who declined to schedule the visit. The authors were unable to determine if the small but statistically significant difference in the percentage of Black or African American patients in the intervention group versus the control population was related to the selection of patients offered the intervention or the patients’ agreement to participate.

Controls were recruited as a convenience sample; they were not matched for age or clinical and demographic features. All that can be reliably discerned from this comparison is that the high satisfaction rates seen in the control population were reproduced among the participants of the NPSBV. In addition, participants in a satisfaction survey following a visit with a known cancer care provider may have felt it was more socially acceptable to respond positively to the clinic and overall care. The one-page SCP used in this intervention was acceptable to providers and patients, but similar tools for communicating survivorship care goals with the primary care team need to be developed.

Implications for Nursing
The success of this model indicates that a NPSBV is a feasible, acceptable method to deliver survivorship care to patients diagnosed with breast cancer. It provides evidence that NPs, as integral team members who have an established relationship with the patient, are appropriate clinicians to deliver survivorship care, and that it can be accomplished without adding significant strain to current resources. Nurses and NPs have been key providers in survivorship care since its inception, and their contributions likely will increase in the coming decades because of workforce shortages among oncologists (American Society of Clinical Oncology, 2008; Grant, Economou, & Ferrell, 2010). As a result, the effectiveness of nurse-led, patient-centered care models to deliver survivorship care should continue to be evaluated.
Conclusion
Cancer survivors comprise an ever-growing proportion of the population and have needs following initial treatment that survivorship care can address. This study provides early evidence that an embedded care NPSBV can deliver this important aspect of care. Future research about an embedded care NPSBV can address measurable improvements in patient outcomes, such as quality of life, distress, and anxiety. The NPSBV model also requires further evaluation of burden to the clinician, use of clinic resources, reproduction in other cancer settings, and evidence for decreased use of healthcare services post-NPSBV.

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