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Survivor PLACE

Evolution of a multidisciplinary approach to survivorship care

Cancer survivorship is recognized as a distinct aspect of the cancer care continuum. The number of cancer survivors has been steadily increasing over the past four decades due to earlier detection, more accurate diagnoses, more effective treatment, improved clinical follow-up, and an aging population.[1] The American Cancer Society estimates that as of January 1, 2012, 13.7 million cancer survivors will be living in the United States, and by 2022, this number is projected to near 18 million.[2] The unique needs of this population with regards to transitioning to a "new normal" after diagnosis and treatment of cancer have led to the development of new models of care.

The Mary Rose Muhr Slemmer Survivor PLACE at Lehigh Valley Health Network (LVHN) is a **P**rogram for patients **L**iving **A**fter the **C**ancer **E**xperience. Designed in response to the Institute of Medicine's (IOM) 2005 report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, Survivor PLACE is an innovative model designed to meet the challenges faced by cancer patients after they complete their primary cancer therapy.

The IOM report documented that too often cancer patients, upon completing their primary cancer treatment, were told by their oncologists "You're doing fine, see you in six months." Accustomed to weekly visits to the oncology office, infusion, and/or radiation centers, patients were left fending for themselves at the completion of treatment. These patients now had no place to address questions or concerns about nutrition, rehabilitation, sexuality, medium- or long-term toxicities of cancer treatment, or simply surviving day to day in a "new normal."[3]

LVHN's journey towards providing survivorship care for our cancer patients began several years ago in response to the attention sparked by the IOM report, increased references to the needs of survivors being published in the literature, and opportunities for learning provided by leaders in survivorship care.

Our Journey

In 2007 our director of Cancer Support Services and our oncology psychiatrist attended the City of Hope training workshop, *Survivorship Education for Quality Cancer Care*. As a result of this workshop, LVHN developed survivorship goals for its cancer program, including:

1. Define survivor program components and develop short- and long-term goals with timelines; present to cancer leadership for approval
2. Present one lecture to professional and ancillary staff about survivorship issues and patient needs
3. Develop, approve, and implement surveillance guidelines for four of our top five cancers.

Administrative support played a key role in moving these goals forward. A literature review and attendance at survivorship conferences helped guide the planning for program components.

In 2008, with the help of local grant funding support, LVHN hired a survivorship coordinator who began by creating a list of internal and external survivorship resources. LVHN then explored grant funding for additional programming. We presented an educational session on cancer survivorship to the professional staff. Additionally, our Cancer Committee approved NCCN-recommended guidelines for surveillance in breast, lung, genitourinary, and colon/rectum and incorporated them into LVHN's cancer care guidelines.

A key planning component was to explore and implement a model for providing survivorship care. In developing our model for survivorship care, we incorporated the following:

- IOM recommendations
- Cancer Care Trajectory from the 2005 IOM report
- Projected Supply and Demand of Medical Oncologists (an ASCO report)
- Survivor feedback through focus groups
- A multidisciplinary approach to care (the Yale Model)
- Steering group.

IOM Recommendations

The IOM report contains 10 recommendations directed towards patients, providers, insurers, researchers, the public, and elected officials. The specific recommendations from the IOM report we chose to focus on for our programming included the following:

- Establish survivorship as a distinct phase of cancer care
- Ensure the delivery of appropriate survivorship care
- Provide patients with a comprehensive treatment summary and follow-up plan
- Develop quality of care measures for survivorship.[3]

We focused our survivorship care on two aspects of the cancer free survival areas of the Cancer Care Trajectory as illustrated in the IOM report:[3]

- The time period after successful treatment with intent to cure prior to recurrence
- Survivorship care for late effects management and surveillance for recurrence and second cancers.

ASCO Report

A study commissioned by ASCO's Board of Directors in 2006 forecasted that demand for oncology services will increase over the next 15 years, driven by the aging population and the increase in cancer survivors.[4] During the same time frame, it is projected that the number of oncologists will not grow to meet the demand. This study forecast a 14 percent increase in visit capacity to meet a 48 percent increase in demand. A possible approach mentioned

The Survivor PLACE team at our Cedar Crest campus (L to R): Diane Brong, LCSW, OSW-C; Denise Fontana, MSN, CRNP; Dorothy Morrone, RN, MS, OCN; Corinne Fillman, MS, CGC; and Jennifer Brennan, RD, CSO, LDN.

to help fill the gap is increased use of other practitioners, including nurse practitioners and primary care practitioners. The projected supply and demand of medical oncologists described in this ASCO report led us to explore a nurse practitioner provider model, outside of the practice setting, and to incorporate documentation through treatment summaries and survivor care plans, to help transition survivors back to primary care.

Focus Groups

We held four focus groups, which included 34 cancer survivors, in the fall of 2008 and the spring of 2009 to gather feedback regarding interest in a survivor clinic. From the focus groups we learned that survivors are wary of the concept of a survivor clinic if they will not be seen by their cancer doctor. The practitioner of the clinic must be knowledgeable and have credibility, so the survivor does not feel as though he or she is being "passed off." We also learned that treatment summaries and care plans are not the standard of care—not a single participant had received one.

Yale Model: CT Challenge 2009

Attendance at Yale Cancer Center's Third Annual Cancer Survivorship Conference, *Creating an Outstanding Cancer Survivorship Program*, in 2009 provided a wealth of information regarding the needs of cancer survivors, as well as some of the nuts and bolts of creating a program. The multidisciplinary model of the CT Challenge Survivorship Clinic at Yale was presented and described by the team involved in running the clinic. This model, in which survivors see several practitioners in one visit, including a nurse practitioner, dietitian, licensed clinical social worker, and rehabilitation specialist, was the model we proposed to LVHN leadership.

Steering Group

Once the proposal for the multidisciplinary survivor clinic was approved by cancer program leadership, we created a survivor clinic steering group to assist in the planning of the clinic. The clinic was incorporated into the Cancer Support Services Department, with the department director chairing the steering group. Members of the group included a physician champion, an administrator, a survivorship coordinator, a nurse manager, a nurse practitioner, a practice manager, an office coordinator from medical oncology, the director of revenue cycle and informatics, and a primary care physician.

The steering group met monthly to develop the clinic's structure and processes. Topics under discussion included:

- Target population
- Scheduling
- Survivor clinic team members
- Billing and reimbursement
- Staffing
- Documentation
- Marketing
- Education
- Outcome measures
- Timelines.

We called our survivorship clinic Survivor PLACE, and the goals included:

- Continued surveillance
- Prevention
- Promotion of a healthy lifestyle
- A process for addressing quality of life issues
- Communication with primary care physicians.

Getting Started

Departmental collaboration was crucial to the success of the survivorship clinic. The certified registered nurse practitioner (CRNP) provider from the medical oncology group at the cancer center helped staff our Survivor PLACE. Her time was paid for out of the Cancer Support Services budget. Our RN survivorship navigator, dietitian, oncology social worker (an LCSW), and support staff were already a part of Cancer Support Services, so Survivor PLACE simply became part of their expected duties. Rehabilitation specialists were assigned to Survivor PLACE by their department, with the expectation that screenings in the clinic would lead to referrals to their service.

The survivorship coordinator researched treatment summaries and care plans, and we chose to use ASCO templates. Working with the steering group and the informatics staff, we modified these templates and incorporated them into the electronic medical record system (MOSAIQ) as Word documents. We created a survivorship packet, which included:

- A quality-of-life questionnaire
- A survivor resource information sheet
- A flyer describing Survivor PLACE
- A treatment summary
- A survivor care plan
- A patient satisfaction survey.

Our survivorship coordinator researched and gathered educational materials and made them readily available at the clinic.

In 2009 we began our survivor clinic as a pilot program. The clinic was offered once a month for three months, with a target of seeing 10 cancer survivors. The pilot allowed us to test the operations and solicit feedback from the cancer survivors we saw at the clinic. The physician champion selected patients from his practice and asked them to volunteer to attend the clinic, free of charge. Eight breast cancer survivors agreed to participate. The pilot ran from October-December 2009. In January 2010, Survivor PLACE officially opened. We held clinics two afternoons a month, with three appointment slots in each clinic.

Survivor PLACE in Operation

Patients are referred to Survivor PLACE by physician or self-referred. Once referred, our RN survivorship navigator schedules the appointment and sends the patient information about the program and a quality-of-life screening questionnaire to be returned prior to the visit. The quality-of-life (QOL) form is home grown, adapted from City of Hope's Quality of Life Cancer Patient/Cancer Survivor Instrument. Our form is shorter (21 items) and focuses on areas that can be addressed by our team at the clinic visit (see pages 28-29). It includes items that address the four domains of quality of life; physical, psychological, social, and spiritual well-being.[5] The form includes a section for survivors to indicate if they would like to meet with someone on the cancer care team and/or receive more information about specific areas (see Table 1, right). Based on their responses to these questions, the team may expand to include a genetic counselor or sex therapist. If patients indicate they are interested in information about diet, they are asked to complete a three-day food diary, also included in the information packet. The cancer survivor is told to expect to spend three hours at their survivor clinic appointment.

Before the visit, our RN survivorship navigator completes a treatment summary for the patient. The team receives the patient list prior to the day of clinic, and is able to view the quality of life screening forms and the treatment summaries in the EMR. At a pre-clinic team meeting, the survivorship navigator reviews the treatment summary and QOL assessment with the team to identify survivorship needs. During clinic, each discipline assesses the patient individually and makes patient-centered treatment and surveillance recommendations. Forty-five minutes are allotted for the CRNP; 30 minutes each for other team members. We can make adjustments to the schedule based on the priority needs of the individual patient.

Our CRNP performs a full history and physical examination. She reviews the treatment history with the cancer survivor, and assesses for post-cancer treatment issues, such as:

- Neuropathy after taxane therapy
- Hearing deficits after platinum therapy
- Hypothyroidism after head and neck radiation
- Cancer-related lymphedema
- Insomnia secondary to anxiety.

Our CRNP also provides information about and referrals to appropriate programs and resources. She then creates the survivorship care plan, including screening and surveillance guidelines, and recommendations for healthy living. The CRNP is the only billing member of the survivorship team.

Many cancer survivors are interested in talking with the dietitian. Weight gain is one of the most common issues addressed, with weight management being the dietitian's number one referral. Patients are also referred by the dietitian to other programs, such as speech therapy for swallowing and chewing dysfunction for patients who have had head and neck radiation. Patients with head and neck cancer are at high-risk for weight loss and enteral nutrition issues. Many cancer survivors have questions about nutritional supplements, use of soy products, plant-based or organic diets, and seek general dietary advice.

Patients are screened by either an occupational therapist or a physical therapist to determine if they have impairments that require skilled rehabilitation. Areas of particular concern include lymphedema, gait or balance impairments, upper or lower extremity pain, weakness range of motion restrictions, neuropathy, and memory or cognition issues. We refer patients that present with rehabilitation needs to one of our outpatient clinics. Patients without impairments requiring skilled services are encouraged to participate in the *Assist to Fitness* program. Funded by a local grant, this program provides a free, three-month gym membership to LVHN's Healthy You Fitness Centers.

Our licensed clinical social worker assesses issues related to depression, anxiety, social support, life satisfaction, financial issues, and fear of the future. Cancer survivors may be referred for formal counseling, or to one of the support groups available within our program or in the community.

The genetic counselor may be scheduled to see cancer survivors if they have indicated an interest, or if there is an identified risk and they have not previously been referred. For cancer survivors who are several years out from treatment, we have found that their family history and/or the genetic testing recommendations may have changed since they were last counseled on their risk.

Lastly, cancer survivors meet with the RN survivorship navigator who reviews the treatment summary and recommendations of all the team members. Follow-up and treatment recommendations are coordinated and scheduled prior to the survivor being discharged. The team develops an individualized care plan, inclusive of prevention and screening recommendations and potential long-term side effects related to cancer treatment. In addition cancer survivors receive a copy of their disease-specific treatment summary, listing staging, procedures, treatments, and complications of therapy. The treatment summary and care plan are

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Table 1. Potential Topics for More Discussion

- I want to know what kind of diet I should follow.
- I want to know what kind of exercise I should be doing.
- I would like to talk with someone about my family's cancer history and hereditary risk of cancer.
- I would like to talk with someone about changes in my sexual life.
- I want to learn more about other services, such as massage, yoga, aromatherapy, etc.
- I would like help understanding how to talk to my family or friends about my cancer.
- I would like emotional support at this time.
- I would like help finding resources in my community.

NAME: DATE OF BIRTH:

Survivor PLACE – QOL Assessment

We are interested in knowing how your cancer experience affects your quality of life. Please answer all of the questions based on your life **at this time**. Circle the number that best describes your experiences.

When you have completed this form, please **mail it back in the enclosed self-addressed stamped envelope.** We will need to review your information prior to your appointment. Thank you.

1. I am fatigued.
no problem 0 1 2 3 4 5 **severe problem**

2. I am having changes in my sleep.
no problem 0 1 2 3 4 5 **severe problem**

3. I have changes in my appetite.
no problem 0 1 2 3 4 5 **severe problem**

4. I have gained/lost weight, unintentionally.
no problem 0 1 2 3 4 5 **severe problem**

5. I have constipation/diarrhea.
no problem 0 1 2 3 4 5 **severe problem**

6. I have nausea/vomiting.
no problem 0 1 2 3 4 5 **severe problem**

7. I have aches/pains.
no problem 0 1 2 3 4 5 **severe problem**

8. I have swelling/edema.
no problem 0 1 2 3 4 5 **severe problem**

9. I have menstrual changes/changes in fertility.
no problem 0 1 2 3 4 5 **severe problem**

10. I have problems remembering things or concentrating.
no problem 0 1 2 3 4 5 **severe problem**

11. I have numbness and tingling since my treatment.
no problem 0 1 2 3 4 5 **severe problem**

12. I have changes in my body/appearance since my treatment.
no problem 0 1 2 3 4 5 **severe problem**

13. I am depressed and/or anxious.
no problem 0 1 2 3 4 5 **severe problem**

14. I am satisfied with my life.
no problem 0 1 2 3 4 5 **severe problem**

15. I am fearful about my future.
no problem 0 1 2 3 4 5 **severe problem**

16. I have a sufficient amount of support from others.
no problem 0 1 2 3 4 5 **severe problem**

17. My personal relationships are satisfactory.
no problem 0 1 2 3 4 5 **severe problem**

18. My sexuality has changed since my cancer diagnosis and treatment.
no problem 0 1 2 3 4 5 **severe problem**

19. I have financial problems since my cancer diagnosis and treatment.
no problem 0 1 2 3 4 5 **severe problem**

20. My family feels distressed since my cancer diagnosis and treatment.
no problem 0 1 2 3 4 5 **severe problem**

21. My daily activities are affected by my cancer diagnosis and treatment.
no problem 0 1 2 3 4 5 **severe problem**

Please mark the things you would like help with or write your own concerns:

☐ I want to know what type of diet I should follow.

If you have indicated an interest in nutrition, please complete the food diary on pages 4 and 5. Be sure to return it with this QOL form.

☐ I want to know what kind of exercise I should be doing.
☐ I would like to talk with someone about my family's cancer history and hereditary risk of cancer.
☐ I would like to talk with someone about changes in my sexual life.
☐ I want to learn more about other services such as massage, yoga, aromatherapy, etc.
☐ I would like help understanding how to talk to my family or friends about my cancer.
☐ I would like emotional support at this time.
☐ I would like help finding resources in my community.

Other concerns:

Please list the physicians to whom copies of Survivor PLACE communications should be sent:

Jennifer Brennan, RD, CSO, LDN, counsels a survivor about nutrition during her visit to Survivor PLACE.

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entered into the EMR and copies are sent to the patients and their designated providers. All patients receive a follow-up phone call after the packet has been mailed to assure that they have received it and to answer any additional questions.

We mail every patient a satisfaction survey and encourage them to provide feedback about the survivorship clinic.

Reimbursement

As mentioned previously, our CRNP is the only billing provider in our survivorship clinic. All other providers are considered part of the hospital-based program, and no facility fee is charged at this time. For patients outside our hospital system, we bill CRNP services as a consultation; if the patient is from within our system, we bill CRNP services as an established patient visit.

Charges for cancer survivor visits mirror the billing for office visits. The cancer diagnosis code is first, because we are following up on the original cancer diagnosis. Additional problems are reflected in additional coding, i.e., neuropathy after taxane therapy. Initial Survivor PLACE visits are usually coded at a level 4 visit. Sometimes the visit is up-coded to a level 5 based on the number of problems and amount of time spent in face-to-face counseling and education. We have had few insurance denials. Financial counseling is available for uninsured and under-insured patients, and grant funding may help cover services as well.

Evolution of Survivor PLACE

Over the course of the past three years, Survivor PLACE has continued to grow—from two clinics a month serving 6 patients, to a weekly clinic serving up to 17 patients a month. Several patients have opted to visit annually. These patients have a more focused visit and may not see all the team members. In 2010 the National Cancer Institute (NCI) selected LVHN as a participating site in its NCCCP (NCI Community Cancer Centers Program). As an NCCCP site we have access to additional resources to meet the needs of our underserved, Hispanic, and inner city populations. As part of this program we hired bilingual staff and in January 2012 we expanded Survivor PLACE to include a monthly clinic at our 17th Street campus, which serves a high percentage of this target population. A bilingual RN survivor navigator coordinates this clinic, supported by bilingual staff.

Table 2. Survivor Place Data Analysis*

	17TH STREET CLINIC	CEDAR CREST CLINIC
	N=26	N=94
SEX		
Women	22	92
Men	4	2
DIAGNOSES		
Breast	19	91
Ovarian	1	1
Lung	0	1
Colo-rectal	2	1
Lymphoma	2	0
CML	1	0
Prostate	1	0
Average Age at Diagnosis	47	53
Average Present Age	53	61
YEARS OUT FROM DIAGNOSIS		
1 to 2	7	12
3 to 5	5	20
6 to 10	10	10
>10	4	26
AVERAGE YEARS OUT FROM DIAGNOSIS		
	5.88	7.96
AVERAGE YEARS OUT FROM DIAGNOSIS (*Removing Those More Than 10 Years Out)*		
	4.54	7.1

*Sample is survivors who completed and returned both an initial and a 3-month QOL form.

Data & Demographics

Data gathered from Survivor PLACE includes race and ethnicity, quality of life, and patient satisfaction. We also review demographic information, including age at diagnosis, current age, years out from diagnosis, sex, and diagnosis. The majority of our patients are female, white, breast cancer survivors, seven to eight years out from diagnosis. The data presented includes the time period between July 2011 to June 2012 for our original site

Table 3. Survivor PLACE Race and Ethnicity*

17TH STREET CLINIC	N-30		CEDAR CREST CLINIC	N-329	
ETHNICITY			ETHNICITY		
Hispanic	20	66%	Hispanic	18	5%
Non-Hispanic	10	33%	Non-Hispanic	308	94%
Unknown	0	0	Unknown	3	1%
RACE			RACE		
American Indian	0	0	American Indian	1	4%
Black	5	17%	Black	1	4%
Asian	4	13%	Asian	7	2%
Mixed	5	17%	Mixed	4	1%
White	9	30%	White	308	94%
Unknown	7	23%	Unknown	8	2%

*From registration data.

Table 4. Data from Survivor PLACE QOL Forms*

	17TH STREET CLINIC		CEDAR CREST CLINIC	
Number and Percent of Survivors Responding	N=30		N=118	
I want to know what type of diet I should follow.	13	43%	41	35%
I want to know what kind of exercise I should be doing.	20	66%	53	45%
I would like to talk with someone about my family's cancer history and hereditary risk of cancer.	13	43%	28	24%
I would like to talk with someone about changes in my sexual life.	14	47%	20	17%
I want to learn more about massage, yoga, aromatherapy, etc.	18	60%	43	36%
I would like help understanding how to talk to my family about my cancer.	10	33%	9	8%
I would like emotional support at this time.	10	33%	10	8%
I would like help finding resources in my community.	14	47%	13	11%

*Data collected January-June 2012 at 17th Street Clinic; July 2011-June 2012 at the Cedar Crest Clinic.

(Cedar Crest), and January through June 2012 for our 17th Street site. Although the numbers are small for our second site, there are remarkable differences in the demographics, showing that we are serving a more diverse population at that site. Our 17th Street patient population is younger, 66 percent Hispanic, more racially diverse, and fewer years out from diagnosis. Comparisons between the two sites are shown in Tables 2 and 3, left and above.

Team-Focused Questions

When asked about specific topics they would like to discuss with someone or learn more about, cancer survivors most commonly chose diet, exercise, complementary therapies, and cancer risk. Forty-seven percent of the 17th Street cancer survivors identified wanting to speak with someone about sexual changes and finding resources in the community as topics of interest (see Table 4, above).

QOL Comparisons

Our 17th Street cancer survivors score higher (higher score = lower QOL) on every item as compared to the cancer survivors at the Cedar Crest clinic. The highest scoring items on the quality of life screen differ between the sites. Both sites rate aches and pains highest, and report "fearful of the future" among the top

Table 5. QOL Scores Reported at the Two Clinic Sites

QOL SCORES: 0 (NO PROBLEM) TO 5 (SEVERE PROBLEM) ON LIKERT-TYPE SCALE

HIGHEST SCORING ITEMS ON QOL SCREEN: 17th Street Clinic (N=26)		At 3 months (N=3)	HIGHEST SCORING ITEMS ON QOL SCREEN: Cedar Crest Clinic (N=118)		At 3 months (N=76)
Aches and pains	2.77	1.66	Aches & pains	1.83	1.05
Financial problems	2.58	1.33	Fatigue	1.34	1.04
Family feels distressed	2.38	1.33	Memory & concentration	1.33	1
Depressed & anxious	2.27	2.33	Changes in sleep	1.3	0.72
Numbness and tingling	2.11	0.33	Sexuality	1.26	1.05
Fearful of future	2.03	2	Fearful of future	1.25	1

six highest scoring items. Top concerns for cancer survivors at the 17th Street clinic include:

- Financial problems
- Family feels distressed
- Depression and anxiety
- Numbness and tingling.

Cancer survivors at the Cedar Crest clinic report these top concerns:

- Fatigue
- Memory and concentration
- Changes in sleep
- Sexuality.

The QOL form is sent to the cancer survivor again three months after the visit. All scores for the top six highest scoring items have trended down at the three-month check (see Table 5, above.)

Questions & Referral Comparisons

At the three-month post-visit, we also track data on recommended referrals and patient report of following through with those referrals (see Table 6, page 33). The most highly recommended referrals are for genetic counseling, dietary issues, psychosocial counseling, rehabilitation services, and testing (bone density, diabetes, genetic testing).

Patient Satisfaction

Satisfaction scores are very high at both survivorship clinic sites. Early in the program we received feedback that cancer survivors were unaware of the time commitment when they came to the clinic. We revised the scripting and informational flyers to emphasize the length of time expected for the Survivor PLACE visit. Other feedback indicates that it would have been very helpful to have had the visit closer to the time they finished treatment. One of our goals is to increase the number of cancer survivors who are seen within the first year of completing treatment.

A Look to the Future

Since starting Survivor PLACE in 2009 research continues to support the importance of survivors developing and/or maintaining a healthy lifestyle, including exercise and weight management.[6-8] Our cancer survivors have shown us that they are interested in learning more about and participating in activities to achieve a healthier "new normal." This information is not traditionally emphasized in an oncology follow-up visit. We had envisioned Survivor PLACE as a stopping-off point before transitioning cancer survivors back to primary care. We are not yet finding this to be the case. Cancer survivors continue to be followed by their oncologists, and several have returned to Survivor PLACE as well for annual visits. Research is showing that oncologists are not yet comfortable transitioning patients to primary care, and that primary care physicians are not yet comfortable taking on cancer survivorship.[9,10] In the meantime, Survivor PLACE is helping to fill a communication gap between oncology and primary care by providing treatment summaries and survivorship care plans. When the projected shortages in the capacity to meet demand for oncology services occur, Survivor PLACE has shown success as a model to assure cancer survivors are not "lost in transition."

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