

# Promotion of self-management for post treatment cancer survivors: evaluation of a risk-adapted visit

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## Abstract

**Purpose** The LIFE Cancer Survivorship Program at NorthShore University HealthSystem provides risk-adapted visits (RAV) facilitated by an oncology nurse during which a survivorship care plan (SCP) is provided and discussed. In this report, we describe and evaluate RAV in promoting individualized health care and self-management during survivorship transition.

**Methods** Patients complete a post-RAV questionnaire at their RAV and another  $\geq 1$  year after their RAV.

**Results** One thousand seven hundred thirteen (1713) RAVs, majority for breast cancer, occurred from January 2007 to March 2014. One thousand six hundred fifteen (1615) “day-of” post-RAV questionnaires were completed. Respondents scaled statements as strongly agree/agree/disagree/strongly disagree. Combined strongly agree/agree ratings are 94 % felt more confident in communicating information about their treatments to other health care providers, 90 % felt more comfortable recognizing signs/symptoms to report to providers, and 98 % had a better appreciation for community programs/services. Of 488 respondents (RAV January 2007 to December 2012  $n=1366$ ) to a questionnaire at least 1 year after the RAV, nearly 100 % found SCP useful to summarize medical information, 97 % to reinforce follow-up, 85 % to recognize symptoms of recurrence, 93 % to identify healthy lifestyle practices, 91 % to assist in identifying resources for support, 72 % discussed their SCP with their healthcare provider, and 97 % made at least one positive lifestyle change.

**Conclusions** Participation in LIFE RAV following treatment helps survivors to guide future self-care behavior. Data suggest that benefits may persist 1 year after the visit and support the feasibility of a nurse-led RAV to establish a SCP in cancer survivors.

**Implications for Cancer Survivors** Combined provision and discussion of SCPs help survivors construct a useful understanding of their cancer experience and may promote long-term self-management.

**Keywords** Cancer survivorship program · Survivorship care plan · Self-management · Patient education · Aftercare · Survivorship transitions in care

## Introduction

The Institute of Medicine’s (IOM) 2005 report, *From Cancer Patient to Cancer Survivor: Lost in the Transition*, brought attention to the healthcare service gap experienced by cancer treatment survivors exiting their treatment regimen and re-entering their pre-treatment lives [1]. The IOM report centers on whether there is provision and discussion of a written survivorship care plan (SCP), including a treatment summary and individualized follow-up plan, as survivors transition out of the “provider intense” cancer treatment environment and back into the primary care setting [2]. A qualitative improvement survey conducted in 2005 of a representative sample of post-treatment cancer survivors at NorthShore University HealthSystem (NorthShore), a four hospital health system in a service area which includes northeast Chicago, and its north and northwestern suburbs, revealed that once survivors completed treatment regimens, they were uncertain where their “new” medical home should be; who, how, and when to return to various health care providers; how to monitor their health; and where to go to marshal other

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health care resources. Within this context, the Living in the Future (LIFE) Cancer Survivorship Program at NorthShore was implemented in November 2006, as a quality of care improvement initiative, with a community education grant from the Lance Armstrong Foundation. Now, in its ninth year, LIFE provides transitional care for adult post-treatment cancer survivors through a multifaceted educational program which includes a risk-adapted visit (RAV) with provision and discussion of a SCP as a distinct phase of care in cancer patients' health care continuum.

As cancer care shifts to a personalized and long-term approach, facilitation of a more active role for survivors in self-management of long-term medical conditions is an increasingly essential component to cancer patients' transition to cost-effective quality care in the primary care environment [3–5]. Analysis of chronic disease self-management programs among Medicare beneficiaries has been shown to improve symptoms, prevent exacerbations of illness, and promote cost savings [4]. In the self-management model, the patient must assume more responsibility for achieving the best outcomes from their care. However, providing information alone does not necessarily improve a cancer survivor's ability to carry out self-care. Educational content and strategies must be personally useful and tailored to address the patient's confidence in their ability to perform a specific activity [5–10]. For example, post-treatment cancer patients may have received information regarding their treatment regimens and possible late effects of their therapy. Yet, survivors may not have the confidence to integrate this knowledge into a meaningful course of action that will help them address future risks or comorbidities [5–12]. In this report, we describe and assess the degree to which an RAV and SCP promote individualized health care and self-management at the re-entry phase as cancer survivors transition from active treatment to follow-up care.

## Methods

### LIFE program process

The LIFE entry point is a consultative, patient-centered RAV for adult cancer patients who have completed active treatment and are referred to the program within one year of completion of primary cancer treatment by a NorthShore medical, surgical, or radiation oncologist. The LIFE program is directed by a physician; a certified oncology nurse is the clinical coordinator and conducts the RAV. The face-to-face visit provides a 1-hour time frame for the provision and discussion of a personalized SCP which is entered into the patient's EPIC (Epic Systems Corporation, Verona, WI) Electronic Medical Record (EMR) and also printed as a patient-friendly portable summary. Referrals to LIFE RAV are made in any one of three ways: (1) by sending an EPIC in-basket message with the patient's

chart attached to the LIFE clinical coordinator; (2) by calling the LIFE LINE; and (3) by placing a cancer survivorship outpatient order in EPIC. Visits take place 5 days/week in any of the three hospital locations where there are NorthShore cancer centers and depend on patient preference and provider availability as to location, time, and date of appointment. There is no charge for participation in the program. The SCP can be accessed in the EMR by all providers in the NorthShore system. Primary care providers are also sent the SCP as a letter through the EPIC system.

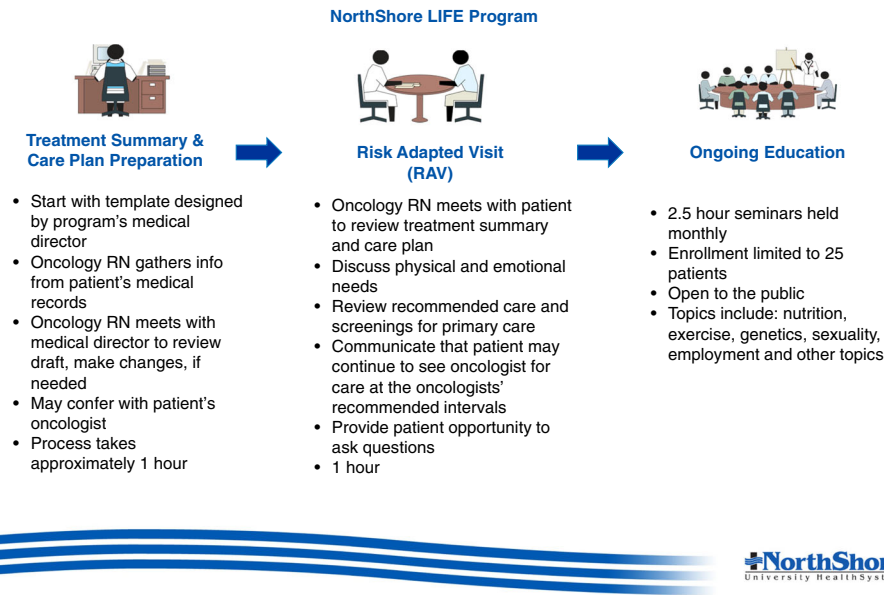
The objectives of the RAV are as follows: (1) to create a strategy for reintegration of the post-treatment cancer patient into the primary care setting; (2) to educate cancer survivors regarding their diagnosis, treatments, and recommendations for preventive health care by provision and discussion of a SCP; (3) to encourage cancer survivors to take an active role in pursuing wellness; and (4) to link cancer survivors to community resources and information that will assist them in their emotional and physical recovery. The LIFE program also offers monthly group education seminars on topics tailored specifically to RAV participants regarding lifestyle (nutrition/fitness), genetics, sexuality, employment, cognition, and lymphedema (Fig. 1).

NorthShore LIFE EPIC SCP templates are designed by the program's medical director with input from NorthShore medical oncologists. The templates follow the most current National Comprehensive Cancer Network (NCCN), American Society of Clinical Oncology (ASCO), and American Cancer Society (ACS) consensus guidelines. The SCP is customized for each patient and includes a treatment summary, guidelines for monitoring recurrence and second malignancy, long-term consequences of cancer treatment, recommended lifestyle modifications, prescribed follow-up care with key clinicians, and navigation to LIFE group workshops and community-based programs.

Prior to the RAV, the oncology nurse gathers information from the patient's EMR and populates most aspects of the SCP. The medical director reviews the SCP draft; the treating oncologist may be conferred with as well. This preparation process takes approximately 1 hour. On the day of the RAV, patients complete a pre-RAV survey tool in the waiting room. The pre-RAV survey tool offers the patient an opportunity to relay immediate concerns elicited from a checklist and also as a free response section. The checklist, developed in 2006, is based on the reported physical, psychological, emotional, social, spiritual, and economic concerns of post-treatment survivors as gleaned from both the literature and from NorthShore's 2005 qualitative improvement post-treatment cancer survivor patient survey [13]. Patient concerns are then reviewed by the LIFE nurse immediately prior to the RAV and incorporated into the SCP. Provision and discussion of the SCP takes place during the RAV. Patients are encouraged to discuss their SCP with their health care providers and to share hard copies of their SCP with providers who do not have access to the EMR version. A supplemental guide is provided containing lifestyle modification

## Empowering Survivors to Take Charge of Their Care

Goal to Make Survivors "Conduits of Information"



**Fig. 1** LIFE program process

guidelines and community, regional, and national programmatic and online survivorship resources.

### Process evaluation: measures and procedures

As part of NorthShore's evaluation of cancer survivorship processes and services, the LIFE program provides an annual report to the NorthShore cancer committee. To that end, LIFE participants are anonymously surveyed in two ways: immediately after their RAV and then at least 1 year after. Surveys were developed to provide a limited set of composite measures that would be outcomes oriented, reflective of reaching RAV objectives/performance, and meaningful for reporting improvement in patients' perception of gaps in care and resource provision that were previously identified as lacking in the 2005 qualitative improvement survey. These surveys are IRB exempt as the surveys meet all criteria on the IRB quality improvement checklist. All surveys are reviewed, tabulated, and recorded by the physician director of LIFE. Descriptive statistics of all evaluations are reported to the NorthShore cancer committee annually.

Patients complete a post-RAV questionnaire on the day of their RAV. Questions are posed to evaluate participants' perception of whether stated objectives of the visit were achieved (Appendix 1). All data are anonymous. The post-RAV evaluation is placed in an envelope and given to the receptionist or placed in a designated inbox in the waiting room. Patients are also permitted to mail in the post-RAV questionnaire.

Follow-up surveys were mailed in 2010 and in 2013 to participants who were at least 1 year after their RAV (RAV

between January 2007 and December 2012). The 2010 survey was sent to those survivors ( $n=670$ ) with a RAV in years 2007, 2008, and 2009. The 2013 survey was sent to survivors ( $n=696$ ) with a RAV in 2010, 2011, and 2012. Questions were posed to evaluate the usefulness of the materials and information derived from the RAV for promoting individualized healthcare and self-management (Appendix 2). The recipients of these surveys were provided with a pre-addressed stamped envelope for mail-in return. Their responses were anonymous.

## Results

### RAV participant characteristics

One thousand seven hundred thirteen (1713) RAVs, the majority for breast cancer, occurred from January 2007 to March 2014. One thousand six hundred fifteen (1615) post-RAV questionnaires were completed with a median time from completion of last therapy of 3 months (Table 1). The most common diagnosis was breast cancer; the median age of participants was 57 years; 89 % were female; and 91 % were white/non-Hispanic. Most identified concerns were cancer recurrence (75 %), late effects of treatment (68 %), cancer prevention/early detection/second cancer (68 %), and nutrition, weight, and lifestyle management (68 %). All survivors had at least one survivorship-related concern, 80 % of survivors experienced more than one survivorship-related concern.

**Table 1** Patient characteristics

Characteristic	A. Initial Post RAV Survey		B. Year-Out Survey Respondents				<i>p</i> Value <sup>a</sup>
	Total ( <i>n</i> =1615)		2010 ( <i>n</i> =234)	2013 ( <i>n</i> =254)	Total ( <i>n</i> =488)		
	No.	%	<i>n</i> (%)	<i>n</i> (%)	No.	%	
<b>Gender</b>							
Female	1432	88.7 %	233 (99.6 %)	244 (96.1 %)	477	97.7 %	<0.0001
Male	183	11.3 %	1 (0.4 %)	10 (3.9 %)	11	2.3 %	
<b>Age</b>							
39 or less	75	4.6 %	9 (3.8 %)	10 (3.9 %)	19	3.9 %	0.2871
40–49	318	19.7 %	49 (20.9 %)	51 (20.1 %)	100	20.5 %	
50–59	555	34.4 %	75 (32.1 %)	84 (33.1 %)	159	32.6 %	
60–64	276	17.1 %	34 (14.5 %)	35 (13.8 %)	69	14.1 %	
65–69	211	13.1 %	34 (14.5 %)	43 (16.9 %)	77	15.8 %	
70+	180	11.1 %	33 (14.1 %)	31 (12.2 %)	64	13.1 %	
Median age	57				56		
Age range	21–98				28–79		
<b>Race</b>							
White/Caucasian	1465	90.7 %	–	–	–	–	–
African American	60	3.7 %	–	–	–	–	–
Hispanic	23	1.4 %	–	–	–	–	–
Asian	55	3.4 %	–	–	–	–	–
Middle Eastern	2	0.1 %	–	–	–	–	–
Hawaiian/Pacific Isle	10	0.6 %	–	–	–	–	–
<b>Time from last treatment</b>							
<6 months	1156	71.6 %	–	–	–	–	–
6–12 months	175	10.8 %	–	–	–	–	–
>12–18 months	284	17.6 %	–	–	–	–	–
Median time	3 months						
<b>Diagnosis</b>							
Breast	1173	72.6 %	208 (88.9 %)	204 (80.3 %)	412	84.4 %	<0.0001
Uterine	69	4.3 %	–	–	–	–	–
Ovarian	62	3.8 %	8 (3.4 %)	14 (5.5 %)	22	4.5 %	0.3099
Lymphomas	65	4.0 %	6 (2.6 %)	10 (3.9 %)	16	3.3 %	0.6621
Colon	37	2.3 %	3 (1.3 %)	4 (1.6 %)	7	1.4 %	0.3449
Rectal	15	0.9 %	–	–	–	–	–
Anal	4	0.2 %	–	–	–	–	–
Melanoma	42	2.6 %	–	–	–	–	–
Prostate	35	2.2 %	–	–	–	–	–
Other	113	7.0 %	9 (3.8 %)	22 (8.7 %)	31	6.4 %	0.9563

Panel A: patient characteristics of respondents to initial post-RAV survey on day of RAV (January 2007 to March 2014), *n*=1615; panel B: patient characteristics of respondents to year-out survey with a RAV (January 2007 to December 2012), *n*=488

RAV risk-adapted visit

<sup>a</sup> Assessed for differences between panel A and panel B survey respondents

### RAV participant perception of benefit

On the post-RAV questionnaire assessing patient perceived benefit of the visit, respondents scaled statements as strongly agree/agree/disagree/strongly disagree. Combined strongly

agree/agree ratings were as follows: 94 % (1518) felt more confident in their ability to communicate information about their cancer treatments to other members of their health care team; 90 % (1454) felt more comfortable recognizing signs and symptoms of recurrence to report to their health care

provider; and 98 % (1583) had a better appreciation for potentially helpful community programs geared to survivorship services. Respondents also graded their perception of the survivorship nurse's knowledge regarding the information covered during the RAV; 95.7 % (1545) felt that the survivorship nurse was knowledgeable about the information discussed during the RAV.

### Characteristics of respondents to evaluation at least 1 year after visit

A total of 488 (35.7 %) survivors responded to the questionnaires sent to participants at least 1 year after their RAV, with 34.9 % respondents to the 2010 survey and 36.5 % respondents to the 2013 survey (Table 2). Characteristics of the respondents to the "year-out" survey are detailed in Table 1 and are predominantly female breast cancer survivors with a median age of 56 years.

### Participant report of usefulness at least 1 year after visit

Survivors were asked to select any of five ways they found the SCP personally useful since the time of their RAV. Of the 488 respondents, nearly 100 % found the SCP a useful tool to summarize medical information, 97 % to reinforce follow-up care, 85 % to recognize symptoms of recurrence to report, 93 % to identify healthy lifestyle practices, and 91 % to assist in identifying resources for support (Table 3). Almost 85 % found the SCP a useful tool in all five domains. Additionally, 72 % stated that they had discussed their SCP with their primary care physician (PCP) or another health care provider; 97 % stated they made at least one positive lifestyle change since their RAV (which included dietary modification with a greater proportion/or more servings of fruits and vegetables, and/or weight management including voluntary weight loss and sustained weight loss, and/or increased physical activity,

and/or discontinuation of non-prescribed supplements); 89 % attended at least one LIFE health promotion seminar and identified which seminar was attended; and 80 % described that they were continuing to work on achieving wellness goals recommended at the RAV (Table 3). The responses derived from the 2010 and 2013 questionnaires were similar, except that patients described discussing their SCP with another health care provider at a greater rate on the 2013 survey (90.6 % compared to 50.9 %). Results of a subanalysis of the 22 ovarian cancer survivors, who responded to the year-out questionnaire (median age 57), mirror the overall results in terms of SCP usefulness, changes in lifestyle behavior, working on wellness goals, and discussing the SCP with PCP or other health professionals (Table 3).

## Discussion

Participation in a nurse-led LIFE RAV following primary cancer treatment helps survivors construct a useful understanding of their cancer experience and guide recommended self-care behavior. These data demonstrate that of the 1615 survivors, who participated in the RAV, most emerged from their RAV more confident with their understanding of their diagnosis, and more confident with their treatment summary and recommendations for post-treatment living and support. Among the minority of survivors who responded to the follow-up survey, the vast majority perceived persistent benefits at least 1 year from the SCP. Providing cancer survivors with understandable information for the purpose of self-navigating transitions in care is at the heart of the 2014 ASCO, and 2013 IOM recommendations on delivery of high-quality cancer care [14–16]. The nurse-managed provision and discussion of the SCP-guided survivors on recommended disease surveillance, and also included the actions they could take for identifying and reporting emerging problems and regaining health. Robust

**Table 2** Year-out survey: number of respondents

Total surveys sent	2010 <i>n</i> =670	2013 <i>n</i> =696	Total <i>n</i> =1366
Year of visit	Response/sent	Response/sent	Response/sent
2007	70/210		70/210 (33.3 %)
2008	78/200		78/200 (39.0 %)
2009	86/260		86/260 (33.1 %)
2010		94/232	94/232 (40.5 %)
2011		75/250	75/250 (30.0 %)
2012		85/214	85/214 (39.7 %)
Total responses/sent	234/670 (34.9 %)	254/696 (36.5 %)	488/1366 (35.7 %)

Years 2010 and 2013 responses to the year-out survey for survivors who had a RAV (January 2007 to December 2012), *n*=488 according to the year of the visit

**Table 3** Results of year out survey responses

	A. All Respondents			B. Ovarian Sub-analysis		
	2010 n=234	2013 n=254	Total n=488	2010 n=8	2013 n=14	Total n=22
RAV/SCP usefulness						
Summarize medical treatment	233 (99.6 %)	252 (99.2 %)	485 (99.4 %)	8 (100 %)	14 (100 %)	22 (100 %)
Reinforce follow-up	227 (97.0 %)	245 (96.5 %)	472 (96.7 %)	8 (100 %)	14 (100 %)	22 (100 %)
Recognize symptoms	192 (82.1 %)	222 (87.4 %)	414 (84.8 %)	5 (62.5 %)	11 (78.6 %)	16 (72.7 %)
Identify LIFEstyle practice	216 (92.3 %)	237 (93.3 %)	453 (92.8 %)	7 (87.5 %)	12 (85.7 %)	19 (86.4 %)
Assist with resources	229 (97.9 %)	216 (85.0 %)	445 (91.2 %)	8 (100 %)	14 (100 %)	22 (100 %)
One or more ways	233 (99.6 %)	254 (100 %)	487 (99.8 %)	8 (100 %)	14 (100 %)	22 (100 %)
Two or more ways	226 (96.6 %)	246 (96.9 %)	472 (96.7 %)	8 (100 %)	14 (100 %)	22 (100 %)
Three or more ways	216 (92.3 %)	236 (92.9 %)	452 (92.7 %)	8 (100 %)	14 (100 %)	22 (100 %)
Four or more ways	212 (90.6 %)	231 (90.9 %)	443 (90.8 %)	7 (87.5 %)	12 (85.7 %)	19 (86.4 %)
Five ways	198 (84.6 %)	216 (85.0 %)	414 (84.8 %)	5 (62.5 %)	11 (78.6 %)	16 (72.7 %)
LIFEstyle change						
Weight management <sup>1</sup>	90 (38.5 %)	87 (34.3 %)	177 (36.2 %)	6 (75 %)	7 (50 %)	13 (59.1 %)
Physical activity <sup>2</sup>	187 (79.9 %)	201 (79.1 %)	388 (79.5 %)	8 (100 %)	14 (100 %)	22 (100 %)
Discontinuation of supplements <sup>3</sup>	80 (34.1 %)	92 (36.2 %)	172 (35.2 %)	4 (50 %)	7 (50 %)	11 (50.0 %)
Fruits/vegetables <sup>4</sup>	192 (82.1 %)	197 (77.5 %)	389 (79.8 %)	7 (87.5 %)	12 (85.7 %)	19 (86.4 %)
One or more change	221 (94.4 %)	252 (99.2 %)	473 (96.9 %)	8 (100 %)	14 (100 %)	22 (100 %)
<sup>1</sup> Voluntary weight loss+sustained weight loss; <sup>2</sup> increase in physical activity, <sup>3</sup> nonprescribed, <sup>4</sup> greater proportion/or more servings of						
Attendance LIFE seminars						
Eat to beat	192 (82.1 %)	202 (79.5 %)	394 (80.7 %)	7 (87.5 %)	12 (85.7 %)	19 (86.4 %)
Insurance/employment	40 (17.1 %)	30 (11.8 %)	70 (14.3 %)	1 (12.5 %)	2 (14.3 %)	3 (13.6 %)
Self-esteem/sexuality	10 (4.3 %)	11 (4.3 %)	21 (4.3 %)	8 (100 %)	11 (78.6 %)	19 (86.4 %)
Genetics	7 (3.0 %)	14 (5.5 %)	21 (4.3 %)	3 (37.5 %)	11 (78.6 %)	14 (63.6 %)
Evening of survivorship	180 (76.9 %)	200 (78.7 %)	380 (77.9 %)	6 (75 %)	13 (92.9 %)	19 (86.4 %)
Food facts and myths	170 (72.6 %)	190 (74.8 %)	360 (73.8 %)	6 (75 %)	13 (92.9 %)	19 (86.4 %)
Chemo brain	N/A	20 (7.9 %)	20 (4.1 %)	N/A	8 (57.1 %)	8 (39.4 %)
Fit for LIFE	96 (41.0 %)	116 (45.7 %)	212 (43.4 %)	6 (75 %)	10 (71.4 %)	16 (72.7 %)
Attended one or more	202 (86.3 %)	232 (91.3 %)	434 (88.9 %)	7 (87.5 %)	12 (85.7 %)	19 (86.4 %)
Continuation of wellness goals						
Weight management	90 (38.5 %)	87 (34.3 %)	177 (36.3 %)	6 (75 %)	7 (50 %)	13 (59.1 %)
Physical activity	187 (79.9 %)	201 (79.1 %)	388 (79.5 %)	8 (100 %)	14 (100 %)	22 (100 %)
Yes	187 (79.9 %)	201 (79.1 %)	388 (79.5 %)	8 (100 %)	14 (100 %)	22 (100 %)
Shared care plan with PCP						
Yes	119 (50.9 %)	230 (90.6 %)	349 (71.5 %)	6 (75.0 %)	10 (71.4 %)	16 (72.7 %)

Panel A: reported usefulness of RAV/SCP from all respondents to year out survey who had RAV (January 2007 to December 2012),  $n=488$ ; panel B: reported usefulness of RAV/SCP from respondents to year out survey who were ovarian cancer survivors and had a RAV (January 2007 to December 2012),  $n=22$

RAV risk-adapted visit, SCP survivorship care plan, PCP primary care provider

evidence in the medical literature supports the effectiveness of nurses in providing meaningful and cost-effective patient education about chronic diseases and secondary preventive strategies for managing chronic conditions [5, 15, 17, 18].

Despite the recent proliferation of outcome measures, valid and widely supported measures of specific survivorship metrics regarding the meaningfulness of survivorship care

planning or promotion of self-management among survivors are not yet available. Research suggests that when using patient-reported outcomes to inform promotion of self-management among cancer survivors, measuring the intervention's "usefulness to patients" is meaningful [10–12]. The literature further suggests that the patient-nurse educational partnership that occurs when there is *discussion* of a SCP can

potentially avert duplicative follow-up, serve as a guide for appropriate health care utilization and surveillance strategies, and act as a motivator for impactful, self-management of healthy lifestyle practices [10, 11, 18–22]. With respect to these parameters, the patient-reported metrics used to evaluate the LIFE RAV demonstrate meaningful use of survivorship care plans by LIFE participants.

The majority (72 %) of all LIFE respondents who were surveyed at least 1 year after their RAV reported discussing their SCP with their PCP and thereby the SCP served as a catalyst of a productive transition back to the primary care environment. In response to the finding that only 51 % of respondents discussed their SCP with another health care provider, the LIFE nurse began placing an enhanced emphasis on “survivor initiated” discussions with survivors’ PCP. This may account for the improvement to 91 % in the 2013 survey. This improvement also emphasized that structured assessments of our program helped to improve the quality endpoints. A nationally representative sample of oncologists and PCPs reveals that PCPs who receive SCPs were nine times more likely to engage with patients in discussion about survivorship issues and were more confident in their follow-up care of survivors; the data also demonstrated that the SCP is an avenue to educate healthcare providers about postcancer therapy long-term care [20, 22]. Our data regarding survivor initiated PCP discussions brought us to conclude that that even with a SCP in the EMR, survivors still need to direct providers’ attention to the SCP to facilitate survivorship-related discussions. As our country moves away from a fee-for-service model toward fixed reimbursement strategies, patients will have to utilize their care plans to navigate their health care, and highlight issues to their providers to ensure that they have the necessary long-term follow-up [20, 23].

Self-efficacy and the behavior process of change, in particular, are important indicators of successful transitions [6]. Most respondents to the survey at least 1 year after their RAV reported that they made positive changes in lifestyle behaviors which were consistent with consensus guidelines presented to them during the RAV. Specifically, 97 % reported that they made at least one of the recommended positive lifestyle changes promoted during the RAV. Almost 80 % reported a continued effort toward their weight management and physical activity goals, and 89 % attended at least one LIFE health promotion seminar. The immediate time period after cancer treatment can serve as a “teachable moment” to motivate patients to adopt risk-reducing behavior [23–25]. The RAV is an opportunity to inform the cancer survivor of the potential benefit of a healthy lifestyle and suggest evidence-based methods for them to achieve this. During the LIFE RAV, survivorship care planning includes detailed instructions on following the American Institute for Cancer Research/World Cancer Research Fund recommendations which parallel the ACS, ASCO, and NCCN consensus guidelines for survivors

[26–31]. These recommendations include being physically active for at least 30 min each day, consuming fewer calories to achieve a healthy weight, eating more fruits and vegetables and less red and processed meat, and discontinuation of any nonprescribed supplements [26–43]. Navigation to the LIFE health promotion seminars and LIFE fitness classes occurs at the time of the visit, and referrals are made to regional lifestyle programs and dieticians when necessary or requested. Thus, survivors are taught how to enlist the support of others, identify healthy lifestyle-related barriers, and are provided with strategies to overcome these barriers.

Strengths of our evaluation of the LIFE RAV include a large sample size, 7 years of comprehensive and contemporary data, and 6 years of “1 year-out” follow-up data. The differences between the patient characteristics of the initial and year-out survey respondents reached significance for female gender and a breast cancer diagnosis; however, the vast majority of respondents in both groups were female breast cancer survivors with no significant differences in age distribution and other cancer diagnoses aside from breast.

Although the RAV model of survivorship care seems to be feasible and successful for effective survivorship care planning for NorthShore HealthSystem, it is important to note the limitations of both the model and its evaluation. The RAV is resource intense; it takes 2 hours of nurse time per RAV. However, at this point, in the rapid trajectory of NorthShore’s electronic medical records system (EPIC), there are aspects of the SCP that are being autopopulated. Thus, preparation time has already decreased significantly since the acquisition of the data reported in the current evaluation. Patients were not charged for the visit. Nevertheless, the time and resources that would be expended by an oncologist for meaningful discussion of survivorship care would come at the expense of waiting time for primary cancer treatment. Therefore, in terms of value for cost, an oncology nurse is considered ideal to establish an SCP.

As participation in an RAV was an option for all cancer survivors who were exiting the treatment environment, the lack of cancer site representativeness is a limitation to internal validity of the evaluation. This discordance may have represented a compliance type characteristic of the population or be the result of a small group of influential referral champions. Patients were primarily female, breast cancer survivors, with nonmetastatic disease, predominantly white non-Hispanic and were seen in the context of our hospital-based cancer centers. However, at NorthShore, breast cancer is our top cancer site and comprises almost 36 % of our post-treatment survivor population—the largest representation of patients who would benefit from the LIFE program. Likewise, the racial demographics of the patients surveyed in the LIFE program closely match NorthShore’s racial demographic.

Due to the factors of time, cost, racial demographic, and cancer representativeness, results may not be generalizable to other healthcare systems, men with cancer or women with other types of cancer aside from breast. However, it should be noted that survivorship concerns among patients in the pre-RAV survey, paralleled concerns of survivors across the country [44].

Due to the anonymity of the evaluative process design, we were unable to make correlations among patient concerns and time since last treatment with program outcomes. Additional limitations may include the overall response rate of 36 % in the year-out data. Response rates in both the 2010 and 2013 datasets were almost identical. Nonresponse bias may challenge the validity and generalizability of results; they may not accurately exemplify the perspectives and self-management practices of the targeted population. Rather, results may represent respondents with positive feelings about their RAV experience and/or respondents who were successful with the advised self-management strategies may be more likely to respond to the survey 1 year after their RAV. Due to the time elapsed in the 2010 and 2013 surveys, patients who had an RAV may not have been able to recall the appointment. Additionally, these results may not be generalizable to those patients referred for a RAV who opted not to pursue one.

Provision and discussion of survivorship care plans may be considered less vital for cancer survivor groups with high risk or more complex cancers than breast cancer. From the ovarian survivor subanalysis data specifically, we can begin to generalize that although discussion of SCPs are potentially critical for cancer survivors who are being completely transitioned from cancer specialty care back to their primary care physician, the variety, quantity, and emphasis of information can be tailored for survivors who are routinely offered long-term specialty follow-up [9, 25, 45].

High-quality evidence evaluating the effectiveness of SCPs and the models to establish them is lacking. The LIFE RAV, a model of nurse-led patient education, is but one example of a consultative survivorship model that may be able to assist post-treatment survivors transition from a provider-intense cancer treatment program to a post-treatment provider partnership and self-management program. There are inherent limitations to the LIFE qualitative improvement initiative, a program that began almost a decade ago, and in the type of research that was done to evaluate the program. Specifically, and perhaps most important, a comparative group is lacking. Well-designed, randomized, controlled trials on SCP delivery models that feature a comparative control group and evidence generated over the long-term investigating several strategies, will ultimately determine optimal evidence-

based approaches. For all stakeholders in survivorship care—consumers, providers, payers, purchasers, and innovators—the definition of value care is ultimately the price that must be paid to achieve meaningful improvement in health outcomes at the level of the individual patient or for the broader population of the growing number of cancer survivors. Like many survivorship programs throughout the USA, NorthShore LIFE does not charge for the survivorship visit and has been able to develop and sustain its program with grant funding and matched funding by NorthShore. Although the funded survivorship program may be a limit to the widespread use of the RAV, there are many aspects of our program model that are generalizable.

Participation in a LIFE RAV following oncology treatment helps survivors construct a useful understanding of their cancer experience to guide self-care behavior. Data suggest that benefits may persist 1 year after the visit. The key to promoting long-term self-management for cancer patients who are exiting the oncology treatment environment may not merely be the written/printed out document known as the SCP, but the *process of relevant discussion* with cancer survivors about the information in that document [7–9, 14, 16, 46–48]. The accreditation committee for the American College of Surgeons Commission on Cancer mandates that cancer survivors receive an individualized SCP that is *clearly and effectively explained* and thereby conjoins both the provision and the discussion of a SCP as a qualitative measure for cancer care [49]. Therefore, the movement toward an all-inclusive packaging of payments for quality cancer care among health care payers should include reimbursement for the cost of *useful* survivorship care planning. As SCP planning is still an unfunded mandate, achieving the widespread national adoption of a SCP that includes relevant discussion will likely depend on appropriate reimbursement for nurse-led preparation and discussion of SCPs.

#### Compliance with ethical standards

**Conflict of interest** Author Thomas Hensing has a consulting role for Boeringer Ingelheim, Roche/Genetech. All authors report no conflict of interest.

**Funding** None.

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. For this type of study, formal consent is not required. The surveys are IRB exempt as the surveys meet all criteria on the IRB quality improvement checklist.



## Appendices

### Appendix 1

#### LIFE Program Post-Risk Adapted Visit Questionnaire

Please take a few moments to complete this questionnaire

#### HISTORY

1. I am a survivor of \_\_\_\_\_ cancer(s)
2. My current age is \_\_\_\_\_
3. I am (circle) Male Female

The objectives of the LIFE Cancer Survivorship Program Risk-Adapted Nurse Visit are:

1. To create an individualized bridge between the oncology treatment setting and living in the future.
2. To educate cancer survivors regarding their diagnosis, treatments, and recommendations for preventive health care by provision and discussion of a portable Survivorship Care Plan.
3. To empower cancer survivors through education to take an active role in pursuing wellness.
4. To link cancer survivors to community resources and information that will assist them in their emotional and physical recovery.

#### As a result of my Risk Adapted Visit and customized Survivorship Care Plan:

I feel more confident in my ability to communicate information about my cancer treatments to other members of my healthcare team.

Strongly agree      Agree      Disagree      Strongly disagree      Not applicable

I feel more comfortable recognizing the important signs and symptoms of recurrence to report to my healthcare providers.

Strongly agree      Agree      Disagree      Strongly disagree      Not applicable

I have a better appreciation of the community programs and services that might benefit me as a cancer survivor.

Strongly agree      Agree      Disagree      Strongly disagree      Not applicable

I feel that the nurse was knowledgeable about the information covered during the Risk- Adapted Visit.

Yes \_\_\_ No \_\_\_

Feel free to list suggestions to make this visit more effective (continue on the back, if needed). All comments are appreciated: \_\_\_\_\_

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## Appendix 2. LIFE program “year-out” follow-up survey

## LIFE Program “Year-Out” Follow-Up Survey

*Thank you for agreeing to complete this questionnaire. We value your input.*

### HISTORY

1. I am a survivor of \_\_\_\_\_cancer(s)
2. My current age is \_\_\_\_\_
3. I am (circle) Male    Female

### YEAR OF VISIT

In what year did your Survivorship visit take place?

- 2006  
 2007  
 2008  
 2009  
 2010  
 2011  
 2012

### SURVIVORSHIP NURSE VISIT (Risk Adapted Visit)

1. Did you find your Survivorship Care Plan a useful tool to: (check all that apply)
  - Summarize your medical information
  - Reinforce your follow up care
  - Recognize symptoms of recurrence to report to your healthcare team
  - Identify lifestyle practices that will promote your health
  - Assist you in identifying local resources for support

Other, please describe:

---

2. Have you shared/discussed your Survivorship Care Plan with any of your healthcare professionals?

Yes  No

If Yes, please list with whom you have shared it (i.e., internist, dentist, family)

---

3. LIFeStyle Changes since your Survivorship Nurse Visit
  - a. Was the information provided regarding weight management helpful to you in working towards meeting or maintaining your BMI (body mass index) goals of 18.5 – 25.0?
 

Yes       No       N/A
  - b. If you needed to lose weight and lost weight after your visit, how much weight did you lose? \_\_\_\_\_lbs

- c. If you lost weight, have you managed to keep this weight off?  
Yes  No
- d. On average how much intentional physical activity do you currently engage in?  
Per day \_\_\_\_\_(minutes) Number of days per week \_\_\_\_\_
- e. Did you increase the amount of your physical activity following your visit?  
Yes  No
- f. Have you decreased the number of unprescribed supplements (with the exception of calcium and Vitamin D) you take since your visit? Yes  No
- g. Do you take a calcium and Vitamin D supplement? Yes  No
- h. On average, how many servings of fruits and vegetables do you eat a day?  
Fruits \_\_\_\_\_ Vegetables \_\_\_\_\_
- i. Did you increase the amount of fruits and vegetables you eat per day since your visit? Yes  No
- j. Did you make at least one lifestyle change based on the recommendations that you received at the visit?  
Yes  No   
If Yes, please describe:  
\_\_\_\_\_
- k. Are you continuing to work on your wellness goals recommended at the visit?  
Yes  No   
If Yes, please describe:  
\_\_\_\_\_

### **SURVIVORSHIP 101 SEMIINAR SERIES**

1. Which of our LIFE Survivorship seminars have you attended?
- Eat to Beat Malignancy, Walk Away from Cancer
  - How LIFE Events Impact Insurance and Employment
  - Self-Esteem and Sexual Intimacy for Women
  - Genetics and the Cancer Survivor
  - Evening of Survivorship
  - Food, Facts and Myths
  - Re-Establishing Intimacy after Cancer
  - Cognitive Dysfunction: Is it Chemobrain?
  - Fit for LIFE: Get Started
  - Lymphedema

**Regarding LIFE Survivorship 101 Seminars**

4. Did you find these seminars helpful? Yes  No  N/A
5. Did you make at least one change based on the information that you received at these seminars?  
Yes  No   
If Yes, please describe:  
\_\_\_\_\_
6. Would you recommend these LIFE seminars to friends and loved ones?  
Yes  No
7. Are there other survivorship related topics that you would like to see presented?  
Yes  No   
If Yes, please describe:  
\_\_\_\_\_  
\_\_\_\_\_

**WEBSITE**

1. Have you accessed our LIFE website ([www.northshore.org/life](http://www.northshore.org/life))?

Yes  No

If Yes, did you access it for information on (check all that apply)

- The LIFE program  
 Survivorship 101 Seminars  
 Survivorship resources  
 Lecture registration

Please feel free to share any additional comments:  
\_\_\_\_\_  
\_\_\_\_\_

**Thank you for completing the LIFE survey.  
Please return it in the enclosed envelope today**

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