How To Develop a Personalized Survivorship Care Plan

By
Cindy Robinson, APRN
Provider for Markey Cancer Center
Multidisciplinary
Long Term Survivorship Clinic

NCI·CC

A Cancer Center Designated by the National Cancer Institute

OBJECTIVES

- Discuss the importance of survivorship care
- Describe the essential elements of a survivorship care plan
- Identify resources available for your practice and patients
- Summarize key components of survivorship care

Cancer Survivorship

- Varying definitions and phases of cancer survivorship
- The National Coalition for Cancer Survivorship, National Cancer Institute, and National Comprehensive Cancer Network define as moment of a cancer diagnosis throughout life
- Mullan (1985) - defines as phases/seasons each with concerns:

  Acute- diagnosis dominated by diagnostic and therapeutic efforts, fear and anxiety dominate feelings.

  Extended- remission/maintenance, has completed rigorous treatment, phase of watchful waiting, diminished strength and fatigue, fear of recurrence.

  Permanent- equated with “cure”, ready to resume a full life, problems with employment and insurance; focus on long term secondary effects of treatment and prevention of subsequent disease.

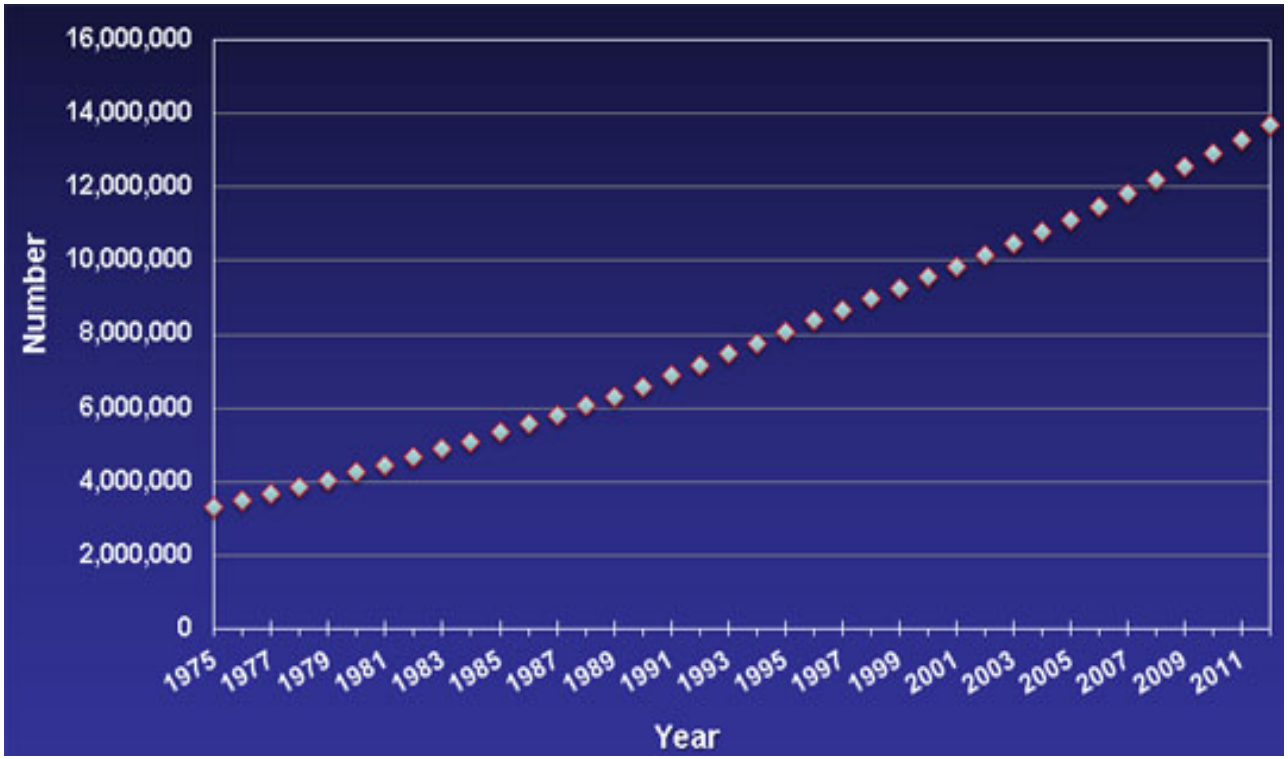
Mullan F. (1985). Seasons of Survival: Reflections of a physician with cancer. *New England Journal of Medicine 313 (4):* 270-273.

Epidemiology of Survivors[1]

- As of January 2012, estimated 13.7 million Americans living with a history of cancer; predicted to increase to 18 million by 2022
- 59% are 65 years or older
- 67% are expected to survive 5 years or longer
- Approximately 15% were diagnosed 20 or more years ago
- Most common sites: female breast (22%), prostate (20%), colorectal (9%) and gynecologic (8%)

[1]Siegal, R., C. DeSantis, et al. (2012). Cancer treatment and survivors statistics. *CA: A cancer Journal for Clinicians 10,* 3322.

The need for Survivorship Care



Estimations and modeling provided by Angela Mariotto, PhD, based on: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010-2020. *J Natl Cancer Inst.* 2011 January 19;103(2):117-28. Epub 2011 Jan 12.

Healthcare Quality Organizations focus on Survivorship

Institute of Medicine (IOM) in 2006 defined survivorship care (SC) as the phase of care following completion of primary treatment, and recommended that it address four essential components:

1) Prevention of recurrent and new cancers and of other later effects

2) Surveillance for cancer spread, recurrence, and secondary cancers, assessment of medical and psychosocial late effects

3) Intervention for consequences of cancer and its treatment

4) Coordination between primary and specialty care

Institute of Medicine and National Research Council of the National Academies. (2006). *From Cancer Patient to Cancer Survivor, Lost in Transition.* Washington, DC: The National Academies Press.

Healthcare Quality Organizations focus on Survivorship (continued)

- IOM proposed 10 key solutions for improving SC[1]
- A top recommendation: all patients completing primary treatment should be provided with a comprehensive care summary and follow-up (f/u) plan called a survivorship care plan (SCP). This should be reimbursed by third party payors.
- SCP would summarize critical information: 1) Cancer type, treatments received, and their potential consequences, 2) Specific information about the timing and content of recommended f/u, 3) Recommendations regarding preventative practices and how to maintain health and well being, 4) Information on legal protections regarding employment and access to health insurance, and 5) Availability of psychosocial services in the community

Institute of Medicine and National Research Council of the National Academies. (2006). *From Cancer Patient to Cancer Survivor, Lost in Transition.* Washington, DC: The National Academies Press.

Healthcare Quality Organizations focus on Survivorship (continued)

- Commission on Cancer (CoC) in 2012 addressed the recommendations of the IOM and updated its standards for accreditation to include performance standards and patient-centered programs[1]

- Key standards in patient-centered areas include: development and dissemination of survivorship care plans, palliative care services, genetics services, navigation programs, and psychosocial distress screening.

- CoC program standard 3.3 mandates that a SCP:
  1) Be prepared by the principle oncology provider(s) who coordinate the oncology treatment for the patient with input from the other care providers
  2) Be given to the patient on completion of treatment
  3) The written or electronic SCP contains a record of care received, important disease characteristics, and a follow-up care plan incorporating available and recognized evidence based standards of care, when available

[1]American College of Surgeons. 2012. Commission on cancer program standards 2012:Ensuring patient-centered care. Retrieved from http://facs.org/cancer/coc/cocprogramstandards2012.pdf

CoC Monitoring Compliance[1]

The program fulfills the following criteria:

- The cancer committee has developed a process to disseminate a comprehensive SCP and follow-up plan to patients who have completed treatment.
- Each year, the process is implemented, monitored, evaluated, and presented to the cancer committee
- Noncompliance - the program does not fulfill one or more of these criteria

[1]American College of Surgeons. 2012. Commission on cancer program standards 2012:Ensuring patient-centered care. Retrieved from http://facs.org/cancer/coc/cocprogramstandards2012.pdf

Models of Survivorship Care

- Transition to primary care model- patients return directly to primary care provider immediately after treatment ends
- Consultative clinic model- offers a one-time comprehensive survivor visit with referral to specialty services if needed
- Integrated care model- ongoing SC provided at original oncology practices, often by nurse practitioners (NPs)
- Disease-specific model- can be costly and requires a large enough survivor population with a particular cancer
- Multidisciplinary clinic model- complex and resource intensive, challenging to have multiple providers at the same time

Integrated Care Model

- Average 30 minutes spent counseling new patients about personalized care plan
- At this visit they are also counsel by our dietician, and American Cancer Society navigator; financial and psych-oncology services if needed.
- Referrals are made to PCPs, smoking cessation counselor, preventative appointments scheduled if appropriate, pain management, physical therapy, speech therapy, genetic counseling, neuro-cognitive evaluation, and oncofertility
- United States Preventative Services Task Force (USPSTF) recommendations given
- Adult immunization recommendations- splenectomy pts.
- Medical/surgical oncology available for possible recurrences or abnormalities on follow-up scans

SCP Templates

- American Society of Clinical Oncology, http://bit.ly/1ddtP7a
- Livestrong®, www.livestrongcareplan.org
- Journey Forward, (developed by National Coalition for Cancer Survivorship; the UCLA Cancer Survivorship Center; WellPoint, Inc.; and Genetech) www.journeyforward.org
- Prescription for Living (developed by Haylock et al., 2007), http://bit.ly/L5C6je

Journey Forward SCP Template

General Information

Patient Name	
Medical record number	
Phone (home)	
Date of birth	7/19/1990
Age at diagnosis	20
Support contact	Mother- Cheryl

Care team	
Hematologist/oncologist	Mara Chambers, nurse-8593236522
Surgeon	Ginger Holt, 6153438612
Radiation oncologist	
Primary care physician	
Nurse/nurse practitioner	
Mental health/social worker	

Journey Forward SCP Template

Background Information

Symptoms/signs	left leg pain
Tobacco use-past	No
Tobacco use-current	No
Cancer type/location	osteosarcoma left distal tibia
Diagnosis date	9/22/2010
New or recurrent cancer diagnosis	New
Surgery	Curative resection
Surgical procedure & findings	per vanderbilt pathology report 12/22/2010- Left BKA, no residual viable osteosarcoma following chemotherapy; greater than 99% necrosis; negative margins
Tumor type/history/grade	outside biopsy slides dated 9/3/2010, reviewed and confirmed by UK pathology, osteosarcoma, osteoblastic type

Staging study	Date	Findings
MRI Left lower extremity	8/23/2010	distal tibial aggressive bone lesion with periosteal expansion and soft tissue mass identified; soft tissue mass measures 8 centimeters.
CT chest without contrast	8/23/2010	No evidence of metastatic disease

T stage	T1
N stage	N0
M stage	M0
Stage	IA

Journey Forward SCP Template

Treatment Plan & Summary

Patient's height	72.5 in	
	Pre-Treatment	**Post-Treatment**
Patient's weight	188 lb	228 lb
Patient's BSA	2.09 m^2	2.3 m^2
Patient's BMI	25.2	30.5
ECOG performance status	1 (Symptomatic but completely ambulatory)	1 (Symptomatic but completely ambulatory)
Comments	Pre-chemotherapy echo LVEF 45%, cardiac work-up negative. Followed by UK cardiology, on lisinopril and coreg. Ineligible to participate in COG secondary to low pre-chemo EF.	

Journey Forward SCP Template

Regimen	Adriamycin, Cisplatin alternating with high dose methotrexate
Treatment on clinical trial	No

Chemotherapy agents	Route	Dose	Schedule	# cycles	% dose reduction
Adriamycin 37.5mg/m2	IV	78mg	every 3 weeks	5	Total dose Adria 375mg/m2
Cisplatin 60mg/m2	IV	125	every 3 weeks	4	
methotrexate 12g/m2	IV	24.7g		10	

Non-chemotherapy agents	Route	Purpose/goal	Comments
Zinecard	IV	Protects heart	

Chemotherapy intent	Adjuvant
Chemotherapy treatment period	10/4/2010-4/25/2011
Possible side effects of regimen	Hair loss, Nausea/Vomiting, Neuropathy, Low blood count, Fatigue, Cardiac
Reason for stopping treatment	Toxicity
Response to treatment	Complete
Treatment-related hospitalization	Yes
Serious toxicities during treatment	prolonged low blood counts
Ongoing toxicities	No
Radiation therapy	Not planned

Journey Forward SCP Template

Follow-up Care

Follow-up care	When / How often?	Coordinating provider
Medical oncology visits	Per National Comprehensive Cancer Network: every 3 months for year 1 (9/11) and 2 (9/12); every 4 months for year 3 (9/13); every 6 months for year 4 (9/14) and 5 (9/15); yearly thereafter	C. Robinson, APRN
Lab tests	as indicated	
Imaging	CT Chest no contrast and bone scan with medical oncology visits	

Potential late effects of treatment	Worsening shortness of breath, pain, fatigue, functional changes, accelerated arthritis in other joints, cosmetic deformity and psychosocial impact.
Symptoms to watch for	worsening shortness of breath/cough/pain/fatigue; loss of appetite, weight loss; cough that doesn't go away; cough blood; nausea/vomiting; blood in stool, change in bowel or bladder pattern, new lumps

Journey Forward SCP Template

Needs or concerns	
Prevention & wellness	Flu vaccine yearly; pneumococcal, pneumonia and Tdap vaccine per Center for Disease Control (CDC) guidelines; bone density, colon cancer screening per United States Preventative Services Task Force (USPSTF) guidelines.
Emotional or mental health	We will provide if needed; Per American Cancer Society, sleep at least 6-7 hours per night and limit alcohol consumption, 2 drinks per day for men. A drink of alcohol is defined as 12 oz. of beer, 5 oz. of wine or 1.5 oz. of 80 proof distilled sprits.
Fertility	pre-chemo sperm banking, patient follow-up

Referrals provided	
Dietician	Per American Cancer Society, healthy weight; eat at least 2.5 cups of fruits and vegetables per day; lean meats, whole grain foods such as breads, rice, pasta and cereals; eat less calories, but more often; avoid skipping meals. Limit consumption of sugar sweetened beverages
Smoking cessation counselor	NOT smoking or using tobacco products is the single best thing you can do to promote life time good health and cancer prevention.
Physical therapist / exercise specialist	Per American Cancer Society, walking everyday 21 minutes- which is 150 minutes per week or 75 minutes of vigorous activity
Social worker	will provide if needed

Journey Forward SCP Template

Comments	-Last Echocardiogram 4/14/2011, left ventricular ejection fraction (LVEF) 54% (Simpson's method); no regional wall motion abnormality. -To promote healthy bones we suggest 1200 milligram (mg) calcium and 600-800 international units (IU) of vitamin D daily. The best source of these vitamins is through your diet. I have included a list of calcium content in foods. -Survivorship care plan given 11/9/11.

Journey Forward SCP Template

Cancer Treatment and Fertility

Some types of cancer treatment can affect a person's fertility, the ability to conceive a child or maintain a pregnancy. Infertility may be temporary or permanent. Whether treatment causes infertility depends on the following:

The type and dose of the drug and how it's given (by mouth, injection, or intravenously [through a vein])

- The dose of radiation given and the area being irradiated
- The type of cancer
- The patient's age and gender
- Whether a patient had fertility problems before cancer treatment

Fertility in a woman may be decreased even if regular menstrual periods continue during treatment or return after treatment. In addition, cancer treatment can cause premature menopause, which shortens the length of time a woman is fertile. Learn more about Pregnancy and Cancer (http://www.cancer.net/vgn-ext-templating/v/index.jsp?vgnextoid=908241eca8daa010VgnVCM100000ed730ad1RCRD&vgnextchannel=83d7ea97a56d9010VgnVCM100000f2730ad1RCRD).

If you are concerned that your cancer treatment will affect your fertility, talk with your doctor. Not all cancer treatments harm fertility, but if the treatment you are receiving does include a risk of infertility, fertility preservation treatments are available. Your chances for maintaining your fertility are greatest if you discuss and think about your options as early as possible.

Journey Forward SCP Template

Options for Preserving Fertility Before Cancer Treatment
This guide focuses on fertility preservation options that are available before cancer treatment. A patient's type of cancer and other personal preferences and circumstances may affect the available options. Many of these methods are investigational, which means that they are still being tested and may not be available to all patients.

For women
- Embryo cryopreservation: the harvesting of eggs followed by in vitro fertilization and freezing of embryos for later use
- Radical trachelectomy: surgery to remove the cervix that leaves the uterus intact
- Oophoropexy or ovarian transposition: surgically moving the ovaries out of the field of radiation
- Other organ-preserving surgery and radiation therapy
- Oocyte (egg) cryopreservation: the collection and freezing of unfertilized eggs (investigational)
- Ovarian tissue cryopreservation: the freezing of ovarian tissue for reimplantation after cancer treatment (investigational)
- Ovarian suppression: the use of hormone therapy to protect ovarian tissue during chemotherapy or radiation therapy (investigational)

For men
- Sperm cryopreservation (sperm banking): the freezing and storing of sperm
- Hormonal gonadoprotection: the use of hormone therapy to protect testicular tissue during chemotherapy or radiation therapy (investigational)
- Testicular tissue cryopreservation and reimplantation: the removal, freezing, and storage of testicular tissue to be surgically reimplanted after cancer treatment (investigational)

Journey Forward SCP Template

Helpful Links

Read the entire *Clinical Practice Guideline* published in the June 20, 2006 issue of the *Journal of Clinical Oncology* (JCO).
(http://www.asco.org/guidelines/fertility)

Fertility and Cancer Treatment
(http://www.cancer.net/vgn-ext-templating/v/index.jsp?vgnextoid=b0d7ea97a56d9010VgnVCM100000f2730ad1RCRD)

Having a Child After Cancer Treatment, Parts I
(http://www.cancer.net/vgn-ext-templating/v/index.jsp?vgnextoid=0aa9462b938be110VgnVCM100000ed730ad1RCRD) and II
(http://www.cancer.net/vgn-ext-templating/v/index.jsp?vgnextoid=96866132c5dfe110VgnVCM100000ed730ad1RCRD)

Journey Forward after Cancer Literature

- Body changes and intimacy
- Financial and legal matters
- Learning to relax
- Managing changes in weight and eating
- Managing fatigue, nervous system changes, pain, your feelings, types of support groups and where to find them
- Social and work relationships
- Lifestyle changes during and after treatment
- Second cancers caused by treatment, overview

Barriers to Implementation

- Limited financial, time and human resources
- Time largest barrier (Dulko et al. 2013; Salz et al. 2012)- average 60-90 minutes per patient
- Reviewing SCP with survivor is substantial, often performed by highly skilled Advanced Practice Providers (APP)
- APP can bill and be reimbursed for delivering an SCP in context of clinical visit, but no reimbursement for time spent in preparing
- Patient barrier – desire to stay with a specific oncologist

Conclusion

- The IOM of the National Academies recommends that federal (CMS, AHRQ, NCI) and private (ACS, health plans) research sponsors support a large new research initiative on cancer patient follow-up (f/u) to answer to the following:

- 1) How frequently pts. be evaluated following primary cancer therapy
  2) What test should be included in the f/u regimen, and
  3) Who should provide f/u care?
- Improvement in cancer survivors care and quality of life depend on this effort

Institute of Medicine and National Research Council of the National Academies. (2006). *From Cancer Patient to Cancer Survivor, Lost in Transition.* Washington, DC: The National Academies Press.

Questions?

June is National Cancer Survivorship Month