Cancer Survivorship Program

Adrienne Vazquez Guerra
March 2019

SYLVESTER COMPREHENSIVE CANCER CENTER
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Cancer Survivorship Program

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Learning objectives

1. Define cancer survivors and common challenges
2. Commission on Cancer (CoC) and other requirements
3. Fertility preservation
4. Case study

Who are cancer “survivors”

Who is a survivor?

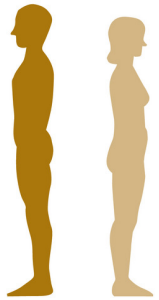
- A cancer survivor is anyone who has been diagnosed with cancer – from the time of diagnosis and for the balance of his or her life.
- An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.
    - Family members, friends, and caregivers are also impacted by the survivorship experience and are included in this definition.

https://www.cancer.gov/about-cancer/coping/survivorship/new-normal

Statistics

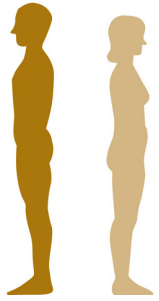
As of January 1, 2019

Male		Female	
Prostate	3,650,030	Breast	3,861,520
Colon & rectum	776,120	Uterine corpus	807,860
Melanoma of the skin	684,470	Colon & rectum	768,650
Urinary bladder	624,490	Thyroid	705,050
Non-Hodgkin lymphoma	400,070	Melanoma of the skin	672,140
Kidney & renal pelvis	342,060	Non-Hodgkin lymphoma	357,650
Testis	287,780	Lung & bronchus	313,140
Lung & bronchus	258,200	Cervix	283,120
Leukemia	256,790	Ovary	249,230
Oral cavity & pharynx	249,330	Kidney & renal pelvis	227,510
All sites	**8,138,790**	**All sites**	**8,781,580**



As of January 1, 2030

Male		Female	
Prostate	5,017,810	Breast	4,957,960
Colon & rectum	994,210	Uterine corpus	1,023,290
Melanoma of the skin	936,980	Thyroid	989,340
Urinary bladder	832,910	Colon & rectum	965,590
Non-Hodgkin lymphoma	535,870	Melanoma of the skin	888,740
Kidney & renal pelvis	476,910	Non-Hodgkin lymphoma	480,690
Testis	361,690	Lung & bronchus	398,930
Leukemia	352,900	Kidney & renal pelvis	316,620
Lung & bronchus	325,680	Ovary	297,580
Oral cavity & pharynx	315,750	Uterine cervix	288,710
All sites	**10,995,610**	**All sites**	**11,174,200**



CA: A Cancer Journal for Clinicians, Volume: 69, Issue: 5, Pages: 363-385, First published: 11 June 2019

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Common challenges

New Normal

The end of cancer treatment is often a time to rejoice. Most likely you're relieved to be finished with the demands of treatment. You may be ready to put the experience behind you and have life return to the way it used to be. Yet at the same time, you may feel sad and worried. It can take time to recover. And it's very common to be thinking about whether the cancer will come back and what happens now. Often this time is called adjusting to a "new normal." You will have many different feelings during this time.

https://www.cancer.gov/about-cancer/coping/survivorship/new-normal

Common Challenges

"It is as if we had invented sophisticated techniques to save people from drowning, but once they had been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can."

Dr. Fitzhugh Mullan

https://www.canceradvocacy.org/about-us/our-history/

Physical changes

- Fatigue
- Bone Loss
- Brain Changes
- Endocrine System Changes
- Hearing Loss
- Heart Problems
- Musculoskeletal Changes
- Lung Problems
- Sexual changes/decreased libido
- Lymphedema
- Mouth Changes
- Infertility
- Neurologic Changes
- Kidney & Liver Issues
- Scars
- Chronic Pain
- Second Primary Cancer

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Psychosocial changes

Depression
Anxiety
Fear of Recurrence
Body Image disturbances
Family Issues (changes in interpersonal relationships)
Unrealistic expectations
Finances (health or life insurance, job loss)

New Normal (return to work/school)
Depression, anxiety (fear of recurrence), uncertainty, isolation, altered body image
Existential/spiritual issues
Sense of purpose or meaning, appreciation of life

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Expansive field

- Cardiac Health
- Obesity
- Psychosocial needs
- Sexual Health/Oncofertility
- Long-term healthcare costs
- Disparities
- Surveillance
- Care coordination

Multidisciplinary care

- Surgery
- Radiation oncology
- Oncology/hematology
- Cardiology
- Primary care
- Genetics
- Endocrine/bone health
- Cancer rehabilitation/PT/OT
- Palliative care
- Sexual health/fertility/Urology/GYN
- Support services
- Specialists

Formal survivorship care

Why do cancer survivorship?

- 2005 IOM report showed:
  - Survivorship care is a neglected phase of cancer care
  - Cancer recurrences, new primaries and treatment late effects are concerns of cancer patients
  - Few guidelines are available for follow up care of the cancer survivor
  - Providers lack education and training

- 2016 Follow up
  - Going Beyond Being Lost in Transition: A Decade of Progress in Cancer Survivorship

Table 1. Institute of Medicine Recommendations (November 2005)

	Recommendation
1	Health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.
2	Patients that complete primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This survivorship care plan should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payors of health care.
3	Health care providers should use systematically developed, evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector efforts.
4	Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.
5	The Centers for Medicare & Medicaid Services, National Cancer Institute, Agency for Healthcare Research and Quality, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.
6	Congress should support Centers for Disease Control and Prevention, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care and promoting the implementation, evaluation, and refinement of existing state cancer control plans.
7	The National Cancer Institute, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality-of-life issues that face cancer survivors.
8	Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment while supporting cancer survivors with short-term and long-term limitations in ability to work.
9	Federal and state policymakers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payors of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.
10	The National Cancer Institute, Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, Centers for Medicare & Medicaid Services, the Department of Veterans Affairs, private voluntary organizations, such as the American Cancer Society, and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives that are focused on cancer patient follow-up are urgently needed to guide effective survivorship care.

Organizations all agree

- Survivorship care is needed! Issues need to be addressed.
    - Oncology Nursing Society (ONS)
    - American Society of Clinical Oncology (ASCO)
    - National Comprehensive Cancer Network (NCCN)
    - American Cancer Society (ACS)
    - National Coalition Cancer Survivorship (NCCS)
    - Commission on Cancer (CoC)
    - Livestrong
    - Institute of Medicine (IOM)
    - Office of Cancer Survivorship (OCS)
    - National Cancer Institute (NCI)

American Cancer Society®

ASCO GUIDELINES

AMERICAN CANCER SOCIETY/AMERICAN SOCIETY OF CLINICAL ONCOLOGY BREAST CANCER SURVIVORSHIP CARE GUIDELINE		
Clinical Domain	**Recommendation**	**Level of Evidence**
Surveillance for Breast Cancer Recurrence		
History and Physical	It is recommended that primary care clinicians:	2A - NCCN guideline
	Should individualize clinical follow-up care provided to breast cancer survivors based on age, specific diagnosis and treatment protocol and as recommended by the treating oncology team.	
	Should make sure the patient receives a detailed cancer-related history and physical examination every 3 to 6 months for the first 3 years after primary therapy, every 6 to 12 months for the next 2 years, and annually thereafter.	2A - NCCN guideline
Screening the breast for local recurrence or a new primary breast cancer	It is recommended that primary care clinicians:	2A - NCCN guideline
	Should refer women who have received a unilateral mastectomy for annual mammography on the intact breast and for those with lumpectomies an annual mammography of both breasts.	
	Should not refer for routine screening with MRI of the breast unless the patient meets high risk criteria for increased breast cancer surveillance as per ACS Guidelines.	2A - NCCN guideline
Laboratory Tests and Imaging	It is recommended that primary care clinicians should not offer routine laboratory tests or imaging, except mammography if indicated, for the detection of disease recurrence in the absence of symptoms.	2A - NCCN guideline

8 pages long!

National Comprehensive Cancer Network®

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Survivorship

Version 2.2019 — June 05, 2019

NCCN.org

246 pages long!

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American Cancer Society

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CANCER A-Z | STAY HEALTHY | TREATMENT & SUPPORT | NEWS | OUR RESEARCH | GET INVOLVED | OUR PARTNERS | ABOUT US

Survivorship: During and After Treatment

In this section you'll find information and tips on staying active and healthy during and after cancer treatment. You can also get information on dealing with the possibility of cancer recurrence, and find inspiration and hope in stories about other people whose lives have been touched by cancer.

Living Well During Treatment

Good nutrition is an important part of cancer treatment, and it's also important to stay as active as you can.

Find Support During Treatment

If you're facing a cancer diagnosis, learning more and connecting with others can be a source of support and comfort. Visit these American Cancer Society resources to find what's right for you.

Moving On and Being Healthy After Treatment

The end of treatment can be both stressful and exciting. You will be relieved to finish treatment, yet it is hard not to worry about cancer coming back.

Patient focused, multiple pages

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PHASE-IN STANDARD

4.8 Survivorship Program

Definition and Requirements

The cancer committee oversees the development and implementation of a survivorship program directed at meeting the needs of cancer patients treated with curative intent.

Survivorship Program Team
The cancer committee appoints a coordinator of the survivorship program per the requirements in Standard 2.1: Cancer Committee.

The Survivorship Program Coordinator develops a survivorship program team. Suggested specialties include physicians, advanced practice providers, nurses, social workers, nutritionists, physical therapists, and other allied health professionals.

The survivorship program team determines a list of services and programs, offered on-site or by referral, that address the needs of cancer survivors. The team formally documents a minimum of three services offered each year. Services may be continued year to year, but it is expected that cancer programs will strive to enhance existing services over time and develop new services.

Each year, the survivorship program coordinator gives a report, and the cancer committee reviews the activities of the survivorship program. The report includes:

- An estimate of the number of cancer patients who participated in the three identified services
- Identification of the resources needed to improve the services if barriers were encountered

Survivorship Program Services
Services utilized by the survivorship program may include, but are not limited to:

- Treatment summaries
- Survivorship care plans
- Screening programs for cancer recurrence
- Screening for new cancers
- Seminars for survivors
- Rehabilitation services
- Nutritional services
- Psychological support & psychiatric services
- Support groups and services
- Formalized referrals to experts in cardiology, pulmonary services, sexual dysfunction, fertility counseling
- Financial support services
- Physical activity programs

Survivorship Care Plans (SCP)
The CoC recommends and encourages that patients receive a survivorship care plan (SCP), but delivery of such plans is not a required component of this standard. Delivery of SCPs may be utilized as one of the services offered to survivors to meet the requirements of this standard. If so, then the program defines the population to receive care plans.

Documentation

Submitted with Pre-Review Questionnaire

- Policy and procedure defining the survivorship program requirements
- Cancer committee minutes that document the required yearly evaluations of the survivorship program

Measure of Compliance

Each calendar year, the program fulfills all of the following compliance criteria:

1. The cancer committee identifies a survivorship program team, including its designated coordinator and members.
2. The survivorship program is monitored and evaluated. A report is given to the cancer committee, contains all required elements, and is documented in the cancer committee minutes.

Bibliography

Jacobs, LA, Shulman LN. Follow-up care of cancer survivors: Challenges and solutions. *Lancet Oncol.* 2017;18:e19-29.

Mayer DK, Nekhyudov L, Snyder CF, Merrill JK, Wollins DS, Shulman LN. American Society of Clinical Oncology clinical expert statement on cancer survivorship care planning. *J Oncol Practice.* 2014;10:345-351.

Nekhlyudov L, Mollica MA, Jacobsen P, Mayer DK, Shulman LN, Geiger AM. Developing a quality of cancer survivorship care framework: Implications for clinical care, research, and policy. *J Natl Cancer Inst.* 2019.

Updated requirements

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Commission on Cancer

- The cancer committee oversees the development and implementation of a survivorship program directed at meeting the needs of cancer patients treated with curative intent.
  - Survivorship program coordinator
  - Survivorship team
  - Yearly report to the Cancer Committee
    - An estimate of the number of cancer patients who participated in the three identified services
    - Identification of the resources needed to improve the services if barriers were encountered

Commission on Cancer

- Update: Survivorship Care Plans (SCPs) are not required.

- Accredited programs in Puerto Rico:
  - San Juan VA Medical Center
  - I. Gonzalez Martinez Oncologic Hospital
  - HIMA - San Pablo Caguas

What's important

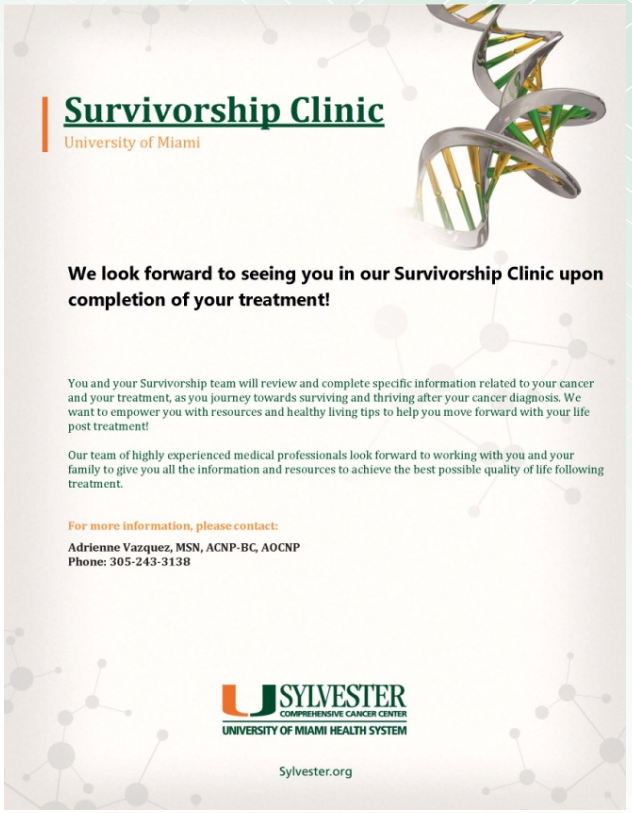
- Communication channels
    - Who does what
    - Understanding of roles and responsibilities of care
- Knowledge transfer
    - Treatment summary and care plan
    - Contact information for providers and nurses
    - Encourage active patient involvement
    - Encourage contacting providers with problems
    - Information on disease, late & long-term effects, follow up
    - Provide the information given to the primary care providers
- Healthy living tips
- Trusted resources
    - Local, national, on-line

What's relayed (Sylvester)

- Survivorship Care Plan:
  - Healthcare providers
  - Diagnosis and Stage
  - Treatment (surgery, chemotherapy, radiation)
  - Long term side effects
  - Information on recurrence or new primary DX
  - Follow up schedule
- Resources & Healthy Living tips
  - UM resources and contact information
  - South Florida and National resources
  - ACS and NCCN guidelines for Healthy Living
  - Additional: flyers or informational sheets

Sylvester Comprehensive Cancer Center

- Oncology Specialist Care
  - Breast clinics
- Consultative Survivorship clinic
  - All other specialists



Other Examples

- Florida Cancer Specialists
    - Consultative Survivorship Clinic
    - Integrated Care
- University of Kansas Cancer Center
    - Consultative Survivorship Clinic
    - Oncology Specialist Care
- MD Anderson Cancer Center
    - Oncology Specialist Care

MD Anderson

Cancer Survivorship Algorithms

Survivorship algorithms depict best practices for care delivery by providing patient management tools to patients under surveillance for cancer recurrence and secondary cancers. Patients are transitioned to Survivorship once there is no evidence of disease for a specific time period dependent on the patient's cancer site. These algorithms are not intended to replace the independent medical judgment of the physician in the context of individual clinical circumstances to determine a patient's care.

Breast Cancer

- Bone Health
- Invasive
- Noninvasive

Gastrointestinal Cancer

- Anal Cancer
- Colon Cancer
- Esophageal Cancer
- Rectal Cancer

Genitourinary Cancer

- Bladder Cancer
- Kidney Cancer
- Penile Cancer
- Prostate Cancer
- Testicular Cancer - Germ Cell
  - Germ Cell Seminoma Stage I Surveillance
  - Germ Cell Seminoma Stage I - Post Adjuvant Radiotherapy or Single-Agent Carboplatin
  - Germ Cell Non-Seminoma Stage I Surveillance
  - Germ Cell Non-Seminoma Stage I - Post RPLND and/or Adjuvant Chemotherapy
  - Germ Cell - All Types, Stages II-IV

Gynecologic Cancer

- Bone Health
- Cervical Cancer (Includes Vulvar and Vaginal)
- Endometrial Cancer
- Ovarian Cancer

Head and Neck Cancer

- Larynx/Hypopharynx Cancer
- Nasopharynx Cancer
- Oral Cavity Cancer
- Oropharynx Cancer
- Salivary Cancer
- Unknown Primary

Leukemia

- Acute Lymphoblastic Leukemia (ALL)
- Acute Myelogenous Leukemia (AML)

Lung

- Non-Small Cell Lung Cancer (NSCLC)

Lymphoma

- Diffuse Large B-Cell Lymphoma
- Follicular B-Cell Lymphoma for Stage I or II
- Hodgkin Lymphoma
- Peripheral T-Cell Lymphoma

Melanoma

- Cutaneous Melanoma

Thyroid Cancer

- Thyroid Cancer

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In Pursuit of Your Wellness

Survivorship Workshop – Miami Beach

Join us on your journey to wellness for a morning with Sylvester physicians and experts that will provide practical tools and resources for those that have completed treatment. This event will offer information sessions on nutrition, sleep, meditation, sexuality, stress management and more. Please dress comfortably in clothes that allow for movement.

February 8th from 9:30 am to 1:00 pm

9:45 am to 10:05 am	Opening – Fear of Recurrence Patient Story and Christina Pozo Kaderman, Ph.D
10:05 am to 10:25 am	Food for Thought: Nutrition for Survivorship Lesley Klein, MS, RD, LD/N
10:25 am to 10:45 am	Sexual Health Christina Pozo Kaderman, Ph.D.
10:45 am to 11:05 am	Yoga Sarah Velar, Wellness Provider
11:05 am to 11:35 am	Break
11:40 am – 12:00 pm	The Vital Role of Sleep and Meditation Michelle Rodriguez Diaz, Clinical Psychologist
12:00 am – 12:20 pm	Stress Management with Music Mary Kauffman, DMA, MT-BC
12:20 pm – 12:40 pm	Question & Answer and Closing Remarks

To RSVP, please click on the link: https://www.eventbrite.com/e/survivorship-workshop-tickets-88730291691
or Contact 305-243-4922

Parking information will follow upon RSVP.

Workshop location: 1741 Collins Ave.
Miami Beach, FL 33139

Sponsored by the Cancer Survivorship Care and Translational Behavioral Sciences Initiative
Sylvester.org

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JOB SEARCH INTENSIVE

This **FREE** in-person event helps patients and survivors navigate the employment landscape after a cancer diagnosis.

SATURDAY, MARCH 21, 2020
9:30 AM - 4:00 PM

(Breakfast & lunch will be provided.)

LOCATION:
Plantation, FL
Exact address will be provided upon acceptance

SPEAKERS:
Rachel Becker, *Senior Director of Programs, Cancer and Careers*
Julie Jansen, *Professional Career Coach & Author*

TO APPLY:
An application must be submitted to be considered for a space. Deadline to apply is Monday, March 2, 2020.

For more **Info,** go to:
www.cancerandcareers.org/en/jobsearchintensive

QUESTIONS:
646.929.8032 or cancerandcareers@cew.org

TOPICS INCLUDE:

- >> ADDRESSING COMMON CONCERNS
- >> IF/WHEN TO DISCLOSE A DIAGNOSIS
- >> GETTING ORGANIZED
- >> RESUMES AND COVER LETTERS
- >> MANAGING THE EMOTIONS OF A JOB-SEARCH
- >> NETWORKING
- >> BUILDING AN ONLINE BRAND
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Research (Sylvester)

- Urology BPA for Fertility preservation
    - Rate of sperm banking increased nearly six-fold after institution of a formal fertility preservation program (June 2016 – August 2017)
    - Fires for both male and female ages 14 - 60
- Survivorship Benefit – A patient's perspective
    - Of the patients surveyed 95.7% were satisfied with the survivorship visit and would recommend this visit to other patients!
    - 59.6% of patients found the SCP to be most helpful, followed by Survivorship Provider input (38.3%) and then American Cancer Society Healthy living tips (36.2%).

Survivorship Research at Sylvester

Background:
The University of Miami has a formal Survivorship Program based on the Commission on Cancer (CoC) requirements. CoC requires accredited institutions to deliver survivorship care plans (SCP) to patients who fit analytic criteria. There is a lack of research on the patient experience as it pertains to survivorship care.

Methods:
Using a Likert-type scale, dual language survey (English and Spanish), patients were asked 6 questions about the Survivorship Clinic visit ranging from scheduling feasibility to information received during the visit and any opinions to improve the visit for future patients. Patients were given two weeks to complete the survey through a secure, HIPAA compliant online source (REDCap). Those who did not reply were called on the phone by a registered nurse to obtain a statistically significant sample size.

Results:
Of the 236 patients that were contacted, 45 responded (Breast 38.3%, Gastrointestinal 12.8%, Prostate 10.6%, Gynecologic 8.5%, Lymphoma 6.4%, Lung 6.4%, Sarcoma 4.3%, Other 12.8%). Our results found that 95.7% of patients would recommend this visit to anyone who has completed cancer treatment. Also, 59.6% of patients found the SCP to be most helpful, followed by Survivorship Provider input (38.3%) and then American Cancer Society Healthy living tips (36.2%). As a note, it was mentioned in free text that 11.1% would have preferred a similar visit at the beginning of treatment, at the completion of treatment and/or incremental follow up. Of those surveyed, 88.9% were referred to nutrition, 44.4% to exercise physiology and 27.8% to psychology/psychiatry.

Conclusions:
Of the patients surveyed 95.7% were satisfied with the survivorship visit. Our conclusion based on survey results shows that institutions should continue to provide formal survivorship care as per CoC requirements. Future directions should look at expanding services to patients at diagnosis and throughout the continuum of treatment and follow up. As survivorship programs grow, practices should consider increasing resources to accommodate the identified needs of patients at the beginning and end of cancer treatment.

Session Type:	Poster Session
Session Title:	Poster Session B: Projects Relating to Patient Experience; Projects Relating to Safety; Technology and Innovation in Quality of Care
Track:	Projects Relating to Patient Experience
Subtrack:	Integrating Patient Experience Assessment and Patient Reported Outcomes into Practice
Abstract #:	183
Citation:	J Clin Oncol 36, 2018 (suppl 30; abstr 183)

Survivors | Survivorship care plans

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Fertility preservation

Fertility preservation: Patient interest

- Recommendation 1.1: People with cancer are interested in discussing fertility preservation. Health care providers caring for adult & pediatric patients with cancer should address the possibility of infertility as early as possible before treatment starts.

- Recommendation 1.2 Health care providers should refer patients who express an interest in fertility preservation (and those who are ambivalent) to reproductive specialists.

- Recommendation 1.3 To preserve the full range of options, fertility preservation approaches should be discussed as early as possible, before treatment starts. The discussion can ultimately reduce distress and improve quality of life. Another discussion/referral may be necessary when the patient returns for follow-up after completion of therapy and/or if pregnancy is being considered. The discussions should be documented in the medical record.

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Fertility preservation: Male options

Recommendation 2.1: Sperm cryopreservation is effective, and health care providers should discuss sperm banking with post pubertal males.

Recommendation 2.2: Hormonal therapy in men is not successful in preserving fertility. It is not recommended.

Recommendation 2.3: Other methods, such as testicular tissue cryopreservation and reimplantation or grafting of human testicular tissue, should be performed only as part of clinical trials or approved experimental protocols.

Recommendation 2.4: Men should be advised of a potentially higher risk of genetic damage in sperm collected after chemotherapy. It is strongly recommended that sperm be collected before initiation of treatment because the quality of the sample and sperm DNA integrity may be compromised after a single treatment.

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Fertility preservation: Female options

Recommendation 3.1: Embryo cryopreservation is an established fertility preservation method, and it has routinely been used for storing surplus embryos after in vitro fertilization.

Recommendation 3.2: Cryopreservation of unfertilized oocytes is an option, and may be especially well suited to women who do not have a male partner, do not wish to use donor sperm, or have religious or ethical objections to embryo freezing.

Recommendation 3.3 Ovarian transposition (oophoropexy) can be offered when pelvic irradiation is performed as cancer treatment. However, because of radiation scatter, ovaries are not always protected, and patients should be aware that this technique is not always successful.

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Fertility preservation: Female options (cont.)

Recommendation 3.4: It has been suggested that radical trachelectomy (surgical removal of the uterine cervix) should be restricted to stage IA2 to IB cervical cancer with diameter < 2 cm and invasion < 10 mm.

Recommendation 3.5: There is conflicting evidence to recommend GnRHa and other means of ovarian suppression for fertility preservation.

Recommendation 3.6: Ovarian tissue cryopreservation for the purpose of future transplantation does not require ovarian stimulation and can be performed immediately. In addition, it does not require sexual maturity and hence may be the only method available in children. This method may also restore global ovarian function. Further investigation is needed to confirm whether it is safe in patients with leukemias.

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Fertility preservation: Providers role

- Recommendation 4.1: All oncologic HCPs should be prepared to discuss infertility as a potential risk of therapy. This discussion should take place as soon as possible once a cancer diagnosis is made and can occur simultaneously with staging and the formulation of a treatment plan.
- Recommendation 4.2: Encourage patients to participate in registries and clinical studies, as available, to define further the safety and efficacy of these interventions and strategies.
- Recommendation 4.3: Refer patients who express an interest in fertility, as well as those who are ambivalent or uncertain, to reproductive specialists as soon as possible.
- Recommendation 4.4: Refer patients to psychosocial providers when they are distressed about potential infertility.

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Fertility preservation: Children

Recommendation 5.1: Suggest established methods of fertility preservation (e.g., semen or oocyte cryopreservation) for postpubertal children, with patient assent and parent or guardian consent. For **prepubertal** children, the only fertility preservation options are **ovarian and testicular cryopreservation**, which are **investigational**.

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Access to care

Reproductive care is part of the standard care of all oncology patients. Cost, access, and time for proven fertility preservation methods may prevent patients from receiving optimal reproductive care.

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Background:

Fertility preservation (FP) prior to therapy is underutilized for those diagnosed with cancer as a child, adolescent or young adult (AYA). This study describes the factors impacting utilization of FP consultations and procedures among childhood and AYA cancer patients at the University of Iowa Health Care (UIHC).

Methods:

Patients were identified by the oncology registry at UIHC. Disease site, histology, date of diagnosis, sex, race, ethnicity, insurance, and zip code were gathered by the registrars. Disease site and histology were categorized using International Classification of Diseases-Oncology-3 (ICD-O-3). UIHC's electronic medical record (EMR, Epic) was queried for ICD codes for FP consultation. Data from UIHC's Reproductive Endocrinology and Infertility clinical database were merged with the primary data set to capture information about those who underwent FP. Rural-Urban Commuting Area codes incorporated a measure of rurality. Descriptive statistics and multivariate linear probability models were used to predict the probability of FP consultation and procedure.

Results:

From 2008-2017, 3,605 children and AYAs were treated for an invasive malignancy. Of the 637 (18%) who received a FP consultation, 162 (25%) underwent a FP procedure. Multivariate analyses showed that those with public insurance or no insurance, a diagnosis of a CNS tumor, melanoma, or miscellaneous neoplasm, and age over 30 years at diagnosis had a lower probability of *having a consultation*. The probability of *undergoing a procedure* was lower for female patients, those with germ cell tumor, melanoma, or carcinoma, seen by a pediatric-based provider, and diagnosed between 15-25 years of age.

Conclusions:

This study has important implications for survivorship and late effects research. The combination of sample identification via cancer registrars and linkage with EMR data could be used by others. The use of federal data to incorporate rurality is frequently overlooked. The use of this type of publicly available data would help improve the robustness of survivorship and late effects research through the inclusion of measures of rurality, health service availability, and economic indicators at varying levels of geography.

First Author:	Erin Michele Mobley, PhD, MPH

Meeting:	2019 Supportive Care in Oncology Symposium
Session Type:	Poster Session
Session Title:	Poster Session B
Track:	Palliative
Subtrack:	Survivorship and Late Effects of Cancer
Abstract #:	139
Citation:	J Clin Oncol 37, 2019 (suppl 31; abstr 139)
DOI:	10.1200/JCO.2019.37.31_suppl.139

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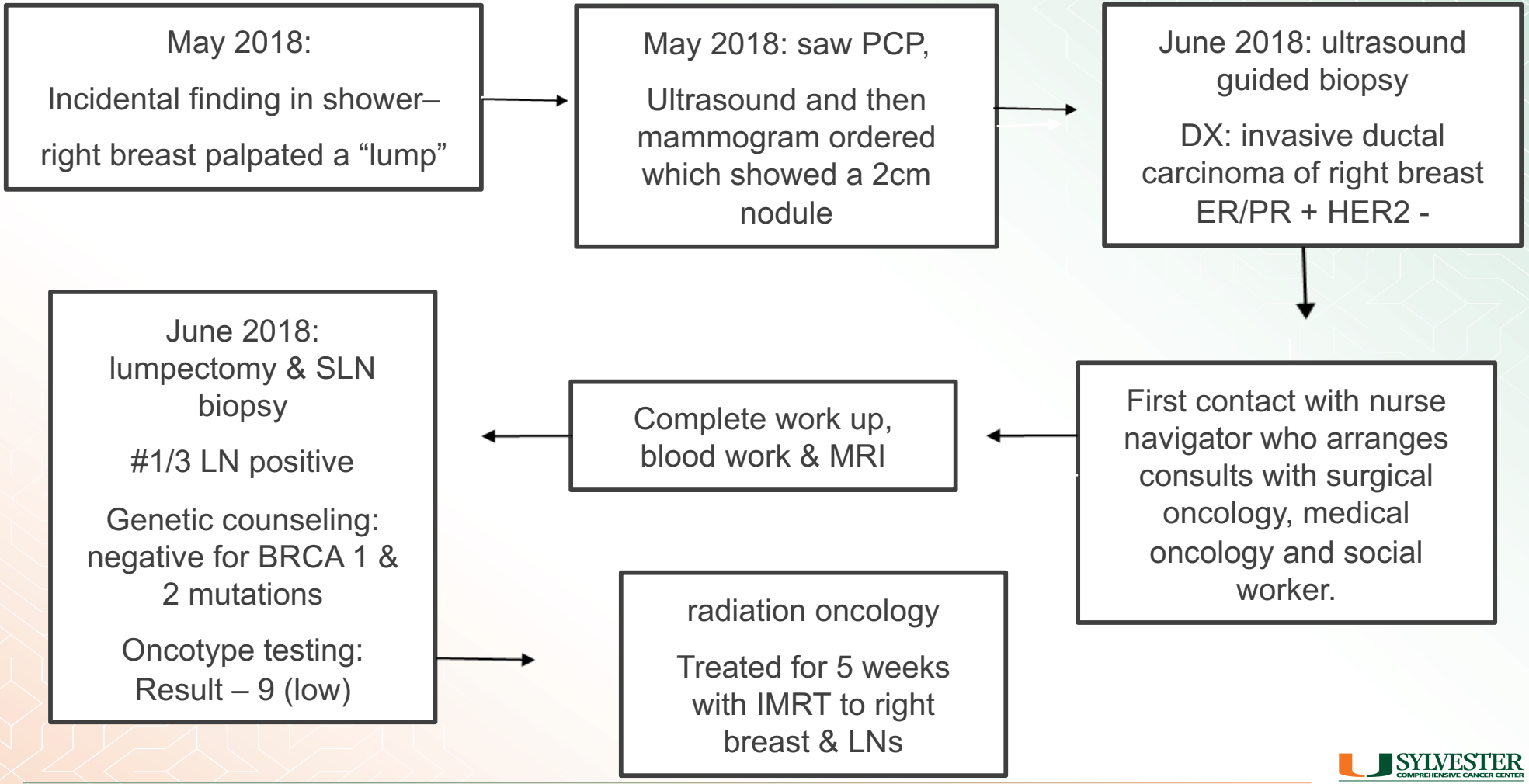
Case study

Case study

35 year old Hispanic female
Married for 2 years
0 children
Business owner
No family history of cancer

NIH defines young adults
As ages 18-35 years



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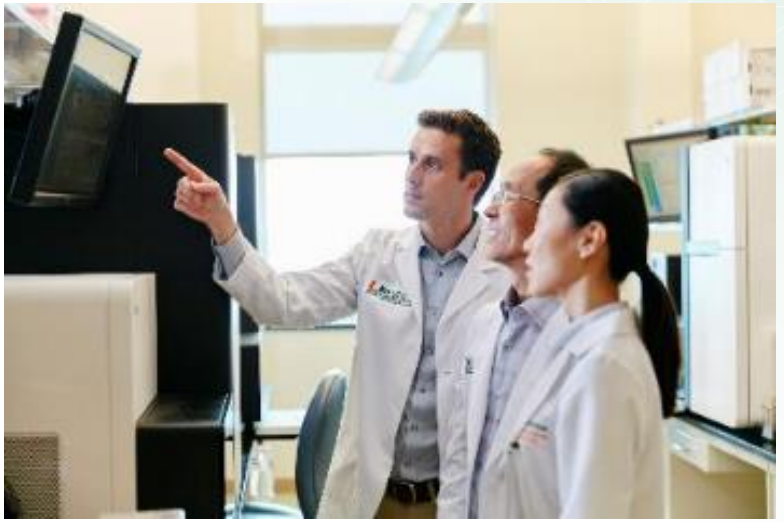
Case study

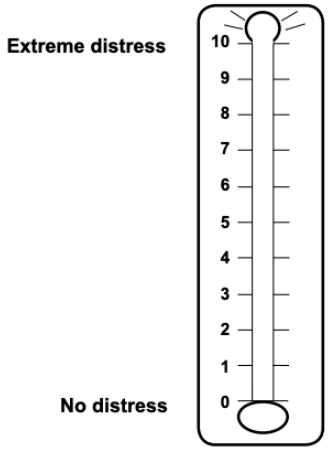
Late August 2018: seen in f/u and RX tamoxifen
November 2018: seen in survivorship clinic



Case study

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.



PROBLEM LIST
Please indicate if any of the following has been a problem for you in the past week including today.
Be sure to check YES or NO for each.

YES	NO	Practical Problems
❑	❑	Child care
❑	❑	Housing
❑	❑	Insurance/financial
❑	❑	Transportation
❑	❑	Work/school
❑	❑	Treatment decisions
		Family Problems
❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
❑	❑	Family health issues
		Emotional Problems
❑	❑	Depression
❑	❑	Fears
❑	❑	Nervousness
❑	❑	Sadness
❑	❑	Worry
❑	❑	Loss of interest in usual activities
❑	❑	**Spiritual/religious concerns**

Other Problems: _____

YES	NO	Physical Problems
❑	❑	Appearance
❑	❑	Bathing/dressing
❑	❑	Breathing
❑	❑	Changes in urination
❑	❑	Constipation
❑	❑	Diarrhea
❑	❑	Eating
❑	❑	Fatigue
❑	❑	Feeling swollen
❑	❑	Fevers
❑	❑	Getting around
❑	❑	Indigestion
❑	❑	Memory/concentration
❑	❑	Mouth sores
❑	❑	Nausea
❑	❑	Nose dry/congested
❑	❑	Pain
❑	❑	Sexual
❑	❑	Skin dry/itchy
❑	❑	Sleep
❑	❑	Substance use
❑	❑	Tingling in hands/feet

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Did anyone ask?

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Case study

”I spoke with the social worker when I was first diagnosed. There was so much information and I remember talking about fertility and wanting children in the future. My husband and I have only been married 2 years, we want children! I have been busy with starting my business and getting it running that we’ve said we would try in a few years. Now all I think about is whether we will be able to have children or not. I am so scared.”

Female statistics (breast cancer)

- Annually, over 120,000 women aged younger than 50 years are diagnosed with cancer in the United States.
- 5-year survival rates are over 75%
- Quality-of-life issues for these survivors, such as fertility, are gaining exposure.
- Many survivors hope to have a biological family.

Safety of pregnancy following breast cancer diagnosis: a meta-analysis of 14 studies.Azim HA Jr, Santoro L, Pavlidis N, Gelber S, Kroman N, Azim H, Peccatori FA Eur J Cancer. 2011 Jan; 47(1):74-83.

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Was she at risk?

1. Chemotherapy/biotherapy?
    a. None
2. Radiation?
    a. Radiation therapy may affect the blood cells and blood supply of the uterus.
3. Hormone therapy?
    a. Tamoxifen does not appear to have permanent effects on menstrual function or fertility but is teratogenic and must be held before and during pregnancy; thus, the need to delay childbearing can pose a risk to fertility through ovarian aging.

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Chemotherapy

1. Cyclophosphamide, included in most adjuvant regimens, appears to be the primary driver of treatment related amenorrhea (TRA).
2. Data informs of small risks of TRA with taxanes (ex: AC-T)
3. Cisplatin was associated with reduced pregnancy rates in males, but not females

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Radiation

1. Ovarian follicles are sensitive to damage from ionizing radiation, which may result in atrophy of the organ and reduced primordial follicle reserve.
2. The ovaries are typically spared significant toxicity from this modality.
3. Of the 50 Gy delivered to the breast during standard whole-breast radiotherapy, only 2.1–7.6 cGy reaches the uterus through internal scatter, which is considerably less than the dose needed to induce POF or cause detrimental effects to the uterus. Because of this small but detectable radiation dose to the pelvis, pregnancy or harvesting of eggs for in vitro fertilization (IVF) should not occur during radiotherapy for breast cancer, but should be possible after treatment is completed.

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Hormone therapy

1. Tamoxifen use following adjuvant chemotherapy is associated with a 2-fold increase in risk of TRA.
2. No women age 40 years or younger treated with tamoxifen alone developed amenorrhea within a large prospective cohort study.
3. Tamoxifen **does not appear to have permanent effects** on menstrual function or fertility.
    a. **Is teratogenic and must be held before and during pregnancy**
4. Although chemotherapy has often been the default approach for young women, optimization of endocrine therapy with ovarian suppression may be a more prudent approach for some with lower risk disease and a means of preserving future fertility.

Curr Treat Options Oncol. 2009 Dec; 10(5-6): 308–317

When to conceive

- Women who are not interested in pregnancy should be encouraged to use adequate contraception.
- Multiple retrospective cohort studies have found no increased risk of cancer recurrence in breast cancer survivors who become pregnant.
    - **Retrospective studies demonstrate that breast cancer survivors who become pregnant after diagnosis had improved survival compared with those who do not become pregnant.**

Safety of pregnancy following breast cancer diagnosis: a meta-analysis of 14 studies.Azim HA Jr, Santoro L, Pavlidis N, Gelber S, Kroman N, Azim H, Peccatori FA Eur J Cancer. 2011 Jan; 47(1):74-83.

Ready to conceive

- One study in breast cancer survivors found a survival benefit in women who waited 2 years or more after diagnosis to attempt conception.
- In cases where the oncology team suggests a 5- to 10-year wait before attempting pregnancy, age can be an important factor.
- Women who are taking tamoxifen are able to ovulate. Need to be on adequate contraception.
    - If interested in conception during this prescribed treatment, discuss how to best incorporate pregnancy into their survivorship plan.

National Cancer Institute, Division of Cancer Control and Population Science Surveillance Research Program, Cancer Statistics Branch. Surveillance, Epidemiology, and End Results (SEER) Program. U.S. population data: 1969–2013.

Other causes

Sexual Dysfunction as an Obstacle to Reproduction

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Communication and documentation

Talk to your patient, LISTEN, understand their needs and what's important to them.

Refer as appropriate.

The Survivorship visit is not the answer. This needs to be addressed at diagnosis and treatment planning.

Summary

1. Cancer survivors face unique challenges. Research shows that though improved, still not being fully addressed.
2. Know your patient resources and relay that information.
3. Fertility preservation should be discussed at diagnosis and during/throughout treatment.
4. There are options, need to look at patient factors (insurance, treatment, age, readiness/desire, culture)

"It is exciting! Everyone on campus is talking about Survivorship."

- UM Sylvester ARNP

"This is exactly what I needed"

- Survivorship clinic patient

"So other people feel the guilt that I do? That I survived and did well..."

- Survivorship clinic patient

“It’s a culture change. We focus on treatment and curing patients, and we do well. Now we are shifting to discuss and address survivorship issues.”

- Dr. J Goodwin