



Cancer Risk Reduction in Indian Country



A Project of Inter-Tribal Council of Michigan, Inc.

Cancer Survivorship Care



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Faculty Disclosure Statement

- Funding for this webinar was made possible by the Centers for Disease Control and Prevention DP18-1808 Consortium of Networks to Impact Populations Experiencing Tobacco-Related and Cancer Health Disparities grant. Webinar contents do not necessarily represent the official views of the Centers for Disease Control and Prevention.
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- The post-webinar survey will be emailed to you after the completion of the course.
- Certificates will be presented digitally upon completion of evaluation.

Learning Objectives/Outcomes

As a result of participating in this activity, the healthcare team will:

1. Examine the American Cancer Society's cancer survivorship care guidelines.
2. Identify the unique aspects of cancer survivorship care coordination for American Indian cancer survivors.
3. Enlist the National Cancer Survivorship Resource Center tools and materials adapted for American Indians to provide American Indian cancer survivors and their families with culturally specific cancer survivorship care coordination.



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Cancer Survivorship Care

Niimigwetch windam maabaa
bimaadiziiwin.

We are thankful for this great life.

Adapted from the National Cancer
Survivorship Resource Center

www.cancer.org/survivorshipcenter



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Acknowledgment

Development of this presentation was made possible by cooperative agreement #5U55DP003054 and #1U38DP004972 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not represent the official views of the Centers for Disease Control and Prevention. The views expressed here do not necessarily reflect the official policies of the U.S. Department of Health and Human Services; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. government.



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Beth Sieloff, MPH, RYT-200

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Introduction



- Your Preferred Name
- Your Role with Tribal Clinics
- What does cancer survivorship mean to you?

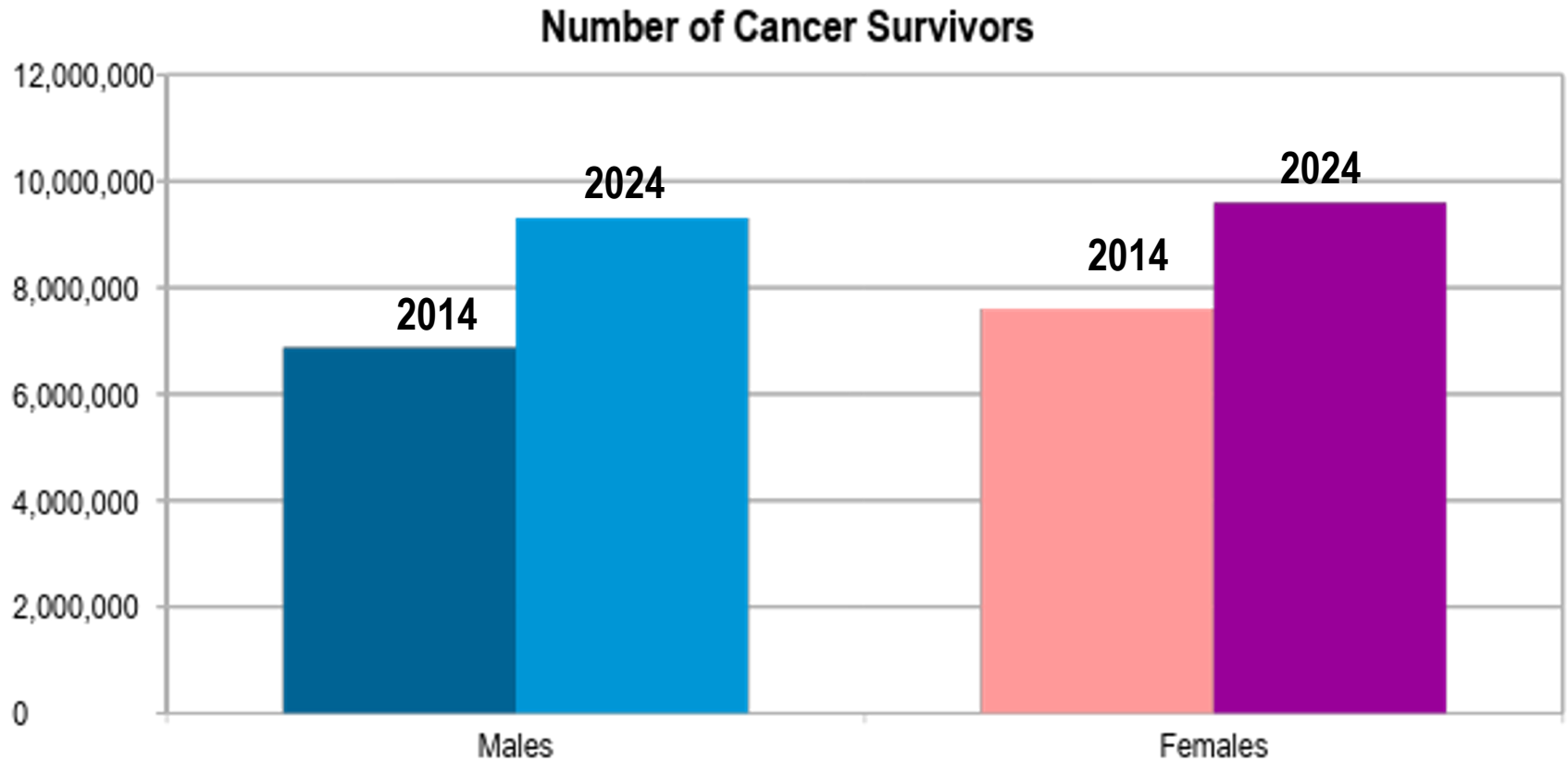


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Focus on Survivorship

(National Statistics)



American Cancer Society, 2014a



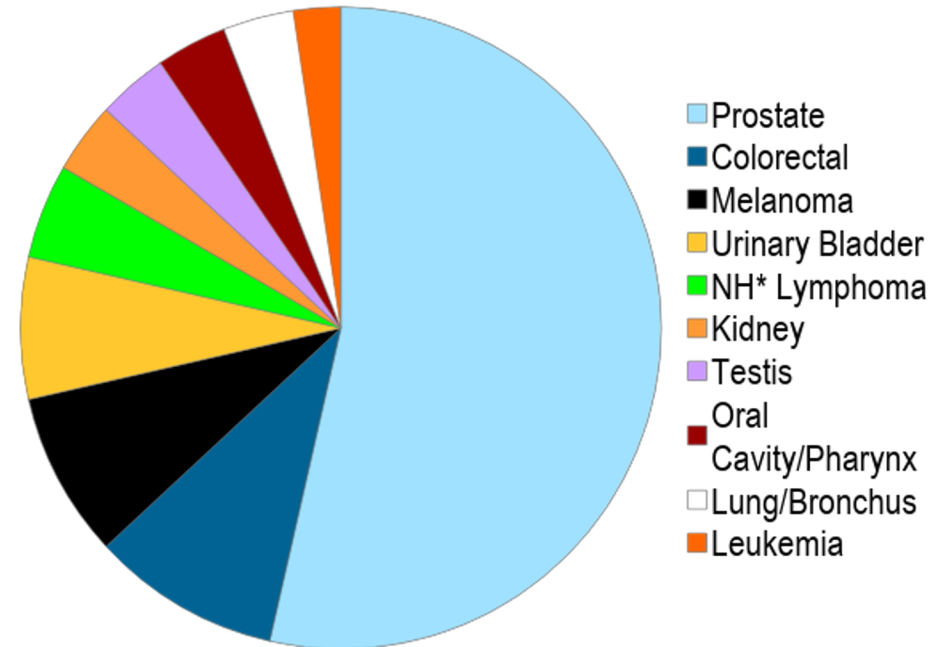
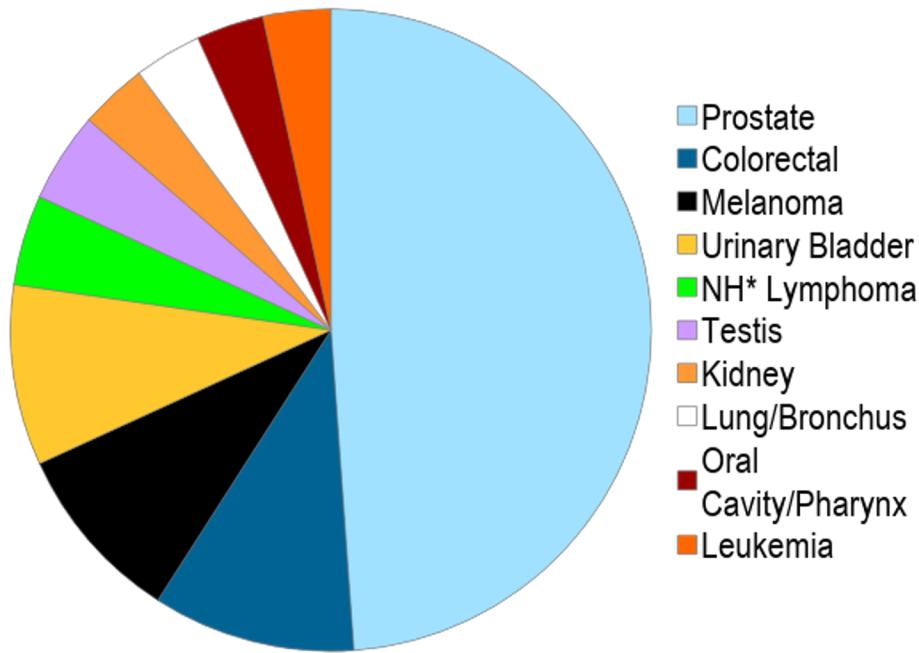
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Focus on Survivorship – Males

2014

2024



*Non-Hodgkin

American Cancer Society, 2014a



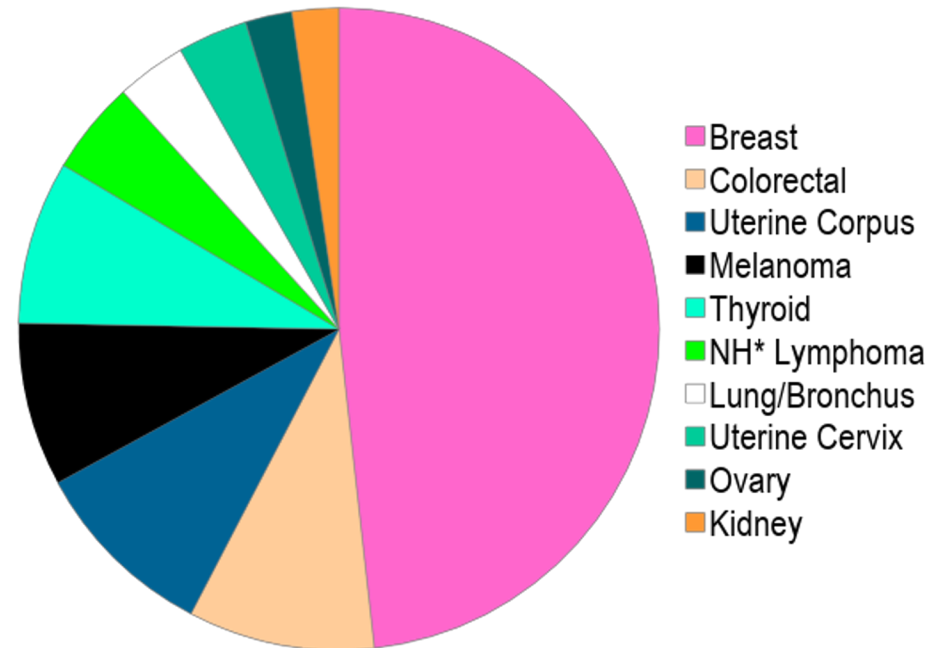
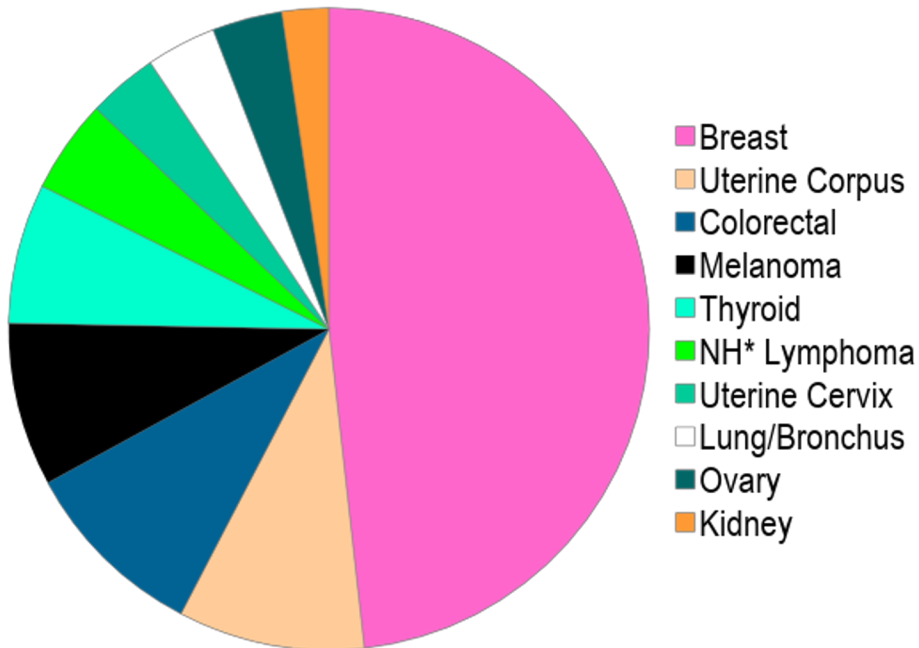
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Focus on Survivorship – Females

2014

2024



*Non-Hodgkin

American Cancer Society, 2014a



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Leading Invasive Cancer Sites

Michigan Residents 2005 - 2014 (Rates per 100,000)

White Male

Rank	Site	Age Adjusted Incidence Rate
1	Prostate Gland	121.0
2	Lung and Bronchus	76.0
3	Urinary Bladder	39.6
4	Colon	29.6
5	Melanoma of Skin	24.2
6	Non-Hodgkin Lymphoma	23.5
7	Kidney and Renal Pelvis	19.6
8	Leukemia	17.2
9	Lip, Oral Cavity and Pharynx	15.6
10	Rectum	14.4

American Indian Male

Rank	Site	Age Adjusted Incidence Rate
1	Lung and Bronchus	120.4
2	Prostate Gland	93.8
3	Colon	48.3
4	Kidney and Renal Pelvis	31.1
5	Rectum	19.9
6	Urinary Bladder	23.7
7	Liver	16.8
8	Non-Hodgkin Lymphoma	15.6
9	Lip, Oral Cavity and Pharynx	15.6
10	Pancreas	14.5

Source : Michigan Resident Cancer Incidence File. Includes cases diagnosed in 2005 - 2014 and processed by the Michigan Department of Health and Human Services, Division for Vital Records and Health Statistics by November 30, 2016.

Leading Invasive Cancer Sites

Michigan Residents 2005 - 2014 (Rates per 100,000)

White Female

Rank	Site	Age Adjusted Incidence Rate
1	Breast	117.6
2	Lung and Bronchus	55.6
3	Colon	25.8
4	Corpus Uteri	26.5
	Non-Hodgkin	
5	Lymphoma	16.6
6	Melanoma of Skin	17.2
7	Ovary	12.0
8	Urinary Bladder	10.1
9	Leukemia	10.8
10	Rectum	10.4

American Indian Female

Rank	Site	Age Adjusted Incidence Rate
1	Breast	103.4
2	Lung and Bronchus	100.3
3	Colon	29.4
4	Kidney and Renal Pelvis	29.1
5	Corpus Uteri	15.8
	Non-Hodgkin	
6	Lymphoma	18.1
7	Rectum	10.7
8	Leukemia	*
9	Ovary	*
10	Cervix Uteri	*

* Rate is considered statistically unreliable.

Source : Michigan Resident Cancer Incidence File. Includes cases diagnosed in 2005 - 2014 and processed by the Michigan Department of Health and Human Services, Division for Vital Records and Health Statistics by November 30, 2016.

Cancer Death Rates

Michigan Residents 2007 - 2016 (Rates Per 100,000)

White Male

Rank	Site	Mortality Rate
1	Lung and Bronchus	58.6
2	Prostate Gland	18.8
3	Pancreas	12.9
4	Colon	13.1
5	Leukemia	24.2

White Female

Rank	Site	Mortality Rate
1	Lung and Bronchus	39.1
2	Breast	19.8
3	Colon	9.7
4	Pancreas	9.3
5	Ovary	7.7

American Indian Male

Rank	Site	Mortality Rate
1	Lung and Bronchus	82.8
2	Colon	23.1
3	Pancreas	*
4	Leukemia	*
5	Prostate Gland	*

*Rate is considered statistically unreliable

American Indian Female

Rank	Site	Mortality Rate
1	Lung and Bronchus	75.0
2	Breast	12.2
3	Colon	11.6
4	Pancreas	*
5	Brain and Other CNS	*

Source : Michigan Residents Death Files, Michigan Department of Health and Human Services, Division for Vital Records and Health Statistics.

American Indian (AI) Survivorship

- Across cancer types, Native people have the worst 5-year survival rates of any U.S. racial or ethnic group.
 - Less likely to receive optimal treatment
 - Lower rate of post treatment surveillance

Javid et al., 2014



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Age-Adjusted Cancer Death Rates U.S. 1990 - 2015

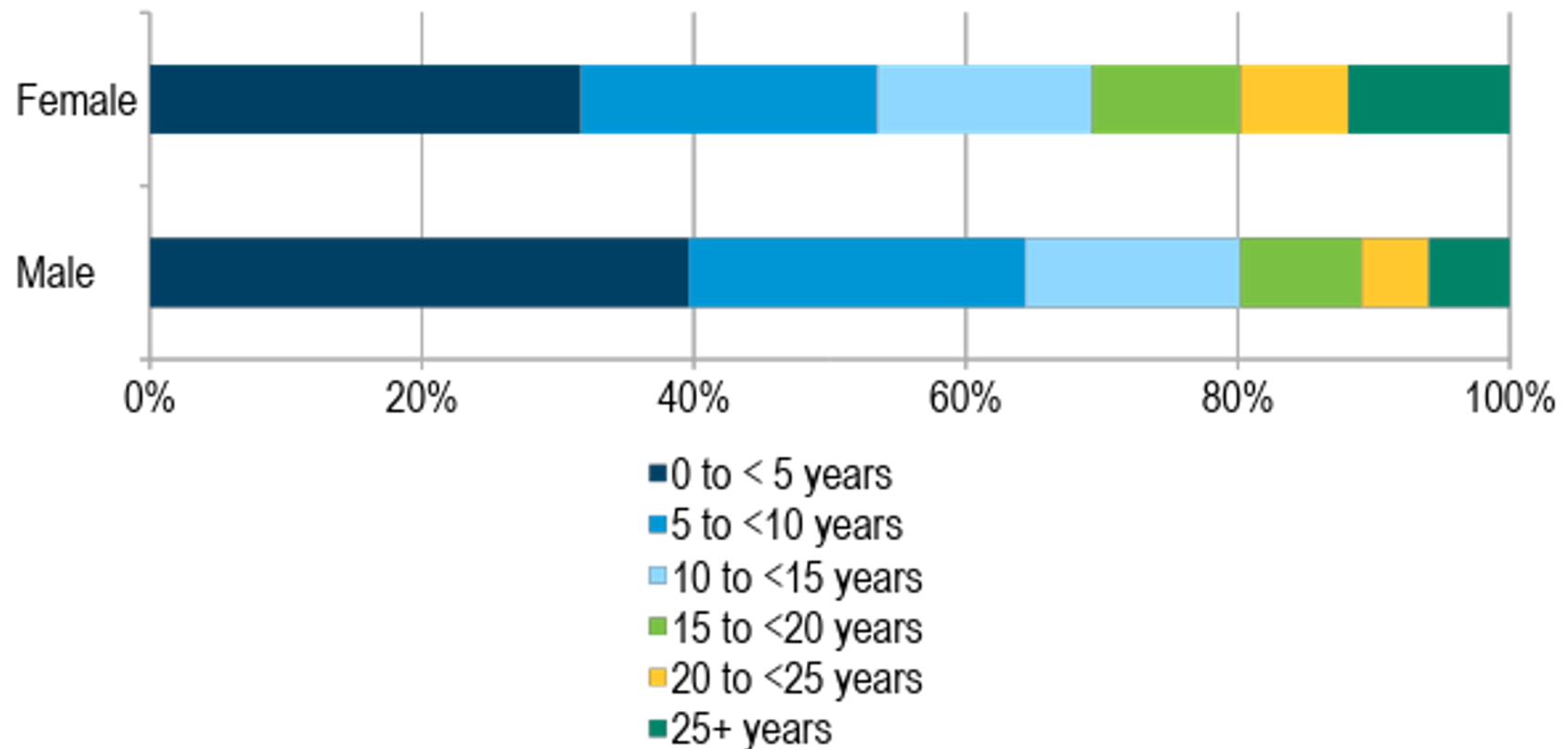
DEMOGRAPHIC FACTOR	AGE-ADJUSTED MORTALITY RATE PER 100,000 ^a						% CHANGE, 1990-2015
	1990	1995	2000	2005	2010	2015 ^b	
Sex							
Male	279.8	268.5	248.5	228.1	208.8	189.2	-32
Female	174.7	173.4	166.7	156.5	145.7	135.6	-22
Age, y							
1-19	3.5	3.0	2.8	2.7	2.3	2.3	-34
20-44	25.3	23.4	21.0	19.0	17.0	16.0	-37
45-64	269.0	246.2	219.8	200.0	182.5	170.1	-37
65-79	986.3	976.7	933.2	859.1	788.8	712.7	-28
≥80	1596.6	1647.1	1640.5	1595.0	1529.0	1430.1	-10
Race/ethnicity							
White ^c	210.8	208.4	199.3	187.2	175	162.3	-23
Black ^c	278.4	272.2	250.6	227.5	206.8	187.2	-33
Hispanic	137.4	139.7	134.7	129.6	119.2	113.8	-17
Asian/Pacific Islander ^c	134.6	134.3	120.1	114.4	108.4	99.7	-26
American Indian/Alaska Native ^{c,d}	158.9	184.9	169.4	177.0	172.3	164.6	+4



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Survivorship by Time Since Diagnosis – U.S. population



American Cancer Society, 2014



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Impacts of Cancer Treatment

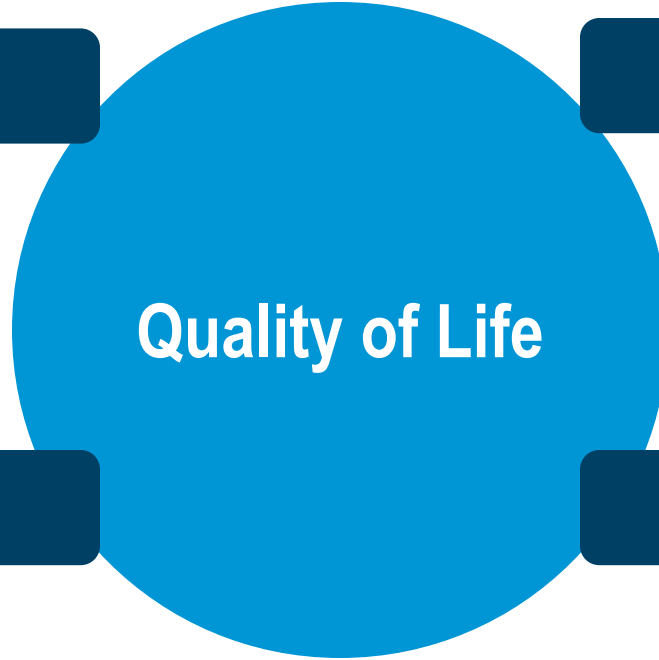
- Individual Effects/Risks
- Surgical Side Effects
- Chemotherapy Side Effects
- Radiation Side Effects
- Hormonal Therapy Side Effects
- Non-Treatment-Specific Side Effects



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The Needs of a Cancer Survivor



Physical Well-Being

- Functional status
- Fatigue and sleep
- Overall physical health
- Fertility
- Pain



Psychological Well-Being

- Control
- Anxiety
- Depression
- Fear of recurrence
- Cognition/attention



Social Well-Being

- Family distress
- Roles and relationships
- Affection/sexual function
- Appearance
- Isolation
- Finances/employment



Spiritual Well-Being

- Meaning of illness
- Religiosity
- Transcendence
- Hope
- Uncertainty
- Inner strength

Ferrell & Hassey Dow, 1997

A Survivor's Story

- Julie White
- [California Rural Indian Health Board, Inc.](#)
- <https://www.youtube.com/watch?v=utll324pJII>



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Cultural Needs of American Indians

- AI cancer patients often have to step outside their cultural norms during cancer treatment (Haozous, E., et al, 2016)
 - Survivorship support requires bidirectional learning by providers to understand the mind, body, spirit and social relationships of indigenous cultures
 - Culturally focused education programs at the community level to inform AI/AN patients about cancer therapies could potentially increase their acceptance among AI/AN populations (Javid, S., et al., 2014)



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Culturally Specific Navigation

Mayo Clinic Cancer Center Patient Navigation

Patient Navigators, serving all cancer patients

- **RST:**
 - Angela Young (1.0 FTE)
 - Brandon Le (1.0 FTE)
- **AZ:** Jodi Ciuk (1.0 FTE)
- **FL:** Open position

Mayo Clinic Cancer Center Patient Navigators are available to provide nonclinical support to cancer patients and their families such as assisting with access to cancer information, resources to help meet day-to-day needs, and emotional support. Patient Navigators can assist patient and caregivers with many needs and work very closely with the social work teams.

- Emotional Support
- Employment Concerns
- Financial Assistance Options
- Insurance Concerns
- Local Community Resources
- Lodging Options
- Navigating Locations
- Transportation Options

Patient Navigators, serving cancer patients, specific populations

- **RST:**
 - Laura Kurland (1.0 FTE) – Hispanic/Latino
 - Schyler Martin (1.0 FTE) – AI/AN
- **AZ:** Trudie Jackson (1.0 FTE) – AI/AN
- **FL:** Veronica Smith (1.0 FTE) – African Descendants

Culturally specific navigators will serve as liaisons between Mayo Clinic patients, their families and their designated communities. The navigators will remain current with resource and referral information and help to identify gaps in resources offered, working with their respective community, as appropriate. Navigators will work collaboratively with staff throughout Mayo Clinic and local service providers to enhance service and referral networks. Identifying needs and facilitating connections in order to decrease barriers to treatment and improve overall patient experience.

Rochester Mayo Contact Info

Main Patient Navigator

☎ 507-266-9288

cecptnavigator@mayo.edu

Angie Young ☎ 507-266-1892

Laura Kurland ☎ 507-266-9351

Schyler Martin ☎ 507-538-6255

Arizona Mayo Contact Info

arzcecptnavigator@mayo.edu

Jodi Ciuk ☎ 480-342-4229

Trudie Jackson ☎ 480-342-0034

Florida Mayo Contact Info

flcecptnavigator@mayo.edu

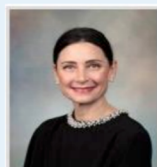
Veronica Smith ☎ 904-953-4034



Angie Young



Brandon Le



Jodi Ciuk

FL Open
Position



Laura Kurland



Schyler Martin



Trudie Jackson



Veronica Smith

Long-term and Late Effects

- **Long-term effects** are medical problems that develop during active treatment and persist after the completion of treatment
- **Late effects** are medical problems that develop or become apparent months or years after treatment is completed



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Potential Physical Impacts



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Potential Long-Term/Late Effects by Treatment Type

Treatment	Long-term side effects	Late side effects
Chemotherapy	<ul style="list-style-type: none"> Fatigue Premature menopause Sexual dysfunction Neuropathy “Chemo brain” Kidney failure 	<ul style="list-style-type: none"> Vision/cataracts Infertility Liver problems Lung disease Osteoporosis Reduced lung capacity Secondary primary cancers
Radiation therapy	<ul style="list-style-type: none"> Fatigue Skin sensitivity Lymphedema 	<ul style="list-style-type: none"> Cataracts Cavities and tooth decay Cardiovascular disease Hypothyroidism Infertility Lung disease Intestinal problems Second primary cancers
Surgery	<ul style="list-style-type: none"> Sexual dysfunction Incontinence Pain 	<ul style="list-style-type: none"> Body image disturbance Functional disability Infertility



Potential Psychosocial Impacts



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General Psychosocial Long-Term and Late Effects

- Depression, depressive symptoms
- Distress
- Worry, anxiety
- Fear of recurrence
- Pain-related concerns
- End-of-life concerns: death and dying
- Changes in sexual function and/or desire
- Challenges with body image
- Challenges with self-image
- Relationship and other social role difficulties
- Return to work concerns and financial challenges

Skoarus et al., 2014



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Cultural Aspects of Long-Term and Late Effects in AI patients

- It is not a cultural norm to discuss many of the long-term and late effects of cancer treatment
 - Primary care provider inquiry to patients well being
 - Develop survivor social networks within tribal communities



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Prevention and Wellness

Tribal health systems are inherently equipped with high quality prevention and wellness programs.



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Empowering Survivors to Live Well

- Prevention
 - Cancer
 - Comorbidities
 - Hypertension, Type 2 Diabetes, Cardiovascular Disease
- General Wellness
 - Diet
 - Exercise
 - Psychological well-being
- Surveillance and Screening

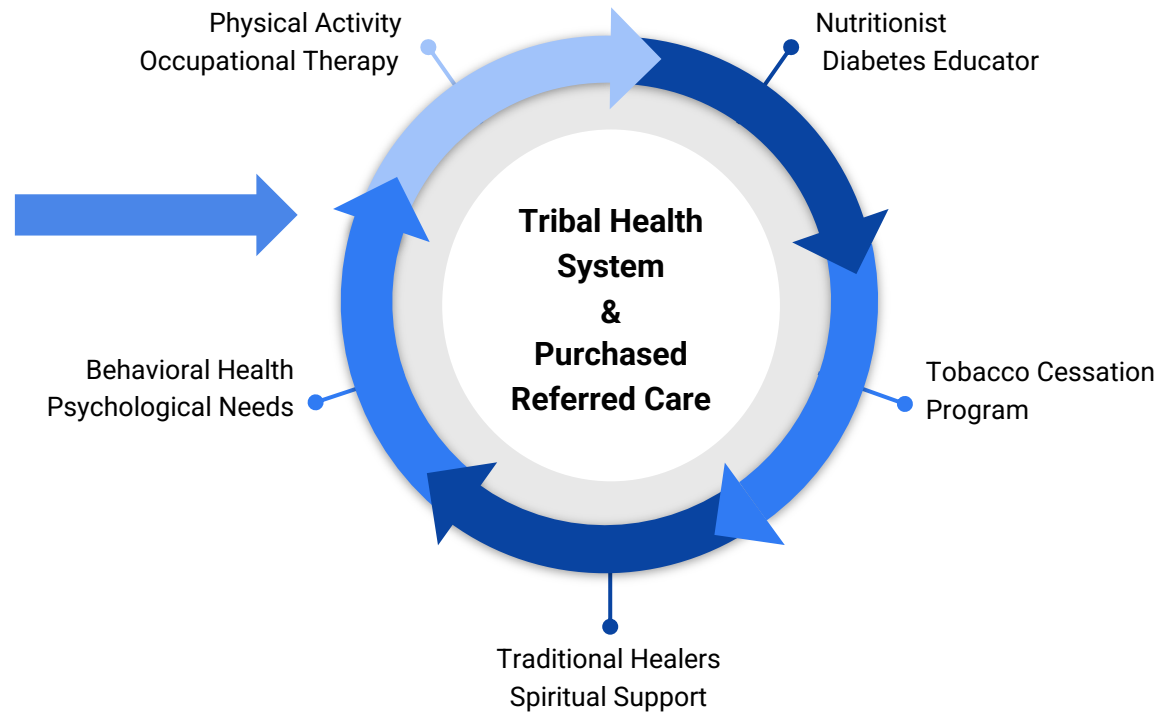


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Tribal Prevention Programs and Services

Utilization of referrals within Tribal Health System and local public health system



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Tribal Prevention Programs and Services

- Utilization of referrals within tribal health system and local public health system.
- Referrals and recommendations by providers are highly regarded in tribal communities:
 - Nutritionist and/or Diabetes Educator
 - Tobacco Cessation
 - Traditional Healers
 - Social, Spiritual, Behavioral and Mental Health Needs
 - Psychologist
 - Follow up care
 - Physical Activity & Occupational Therapy
 - Physical/Occupational Therapists
 - Fitness classes at local gym
 - Traditional dancing
 - Financial Assistance
 - Assistance with purchase referred care



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ACS Nutrition and Physical Activity Guidelines for Cancer Survivors

Achieve and maintain a healthy weight



- If overweight or obese, limit consumption of high-calorie foods and beverages and increase physical activity to promote weight loss

Engage in regular physical activity



- Avoid inactivity and return to normal daily activities as soon as possible following diagnosis
- Aim for aerobic exercise at least 150 - 300 minutes per week
- Include strength training exercises at least 2 days per week

Achieve a dietary pattern that is high in vegetables, fruits and whole grains



Follow the American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Prevention



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Spirituality



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Spirituality

Studies indicate that spirituality:

- Helps patient with chronic illness, better quality of life and end-of-life
- Increases one's will to live
- Improves coping skills, sense of coherence, meaning
- Improves stress management (meditation, spiritual practices, mindfulness)
- Improves pain management
- Enables patient to have more realistic sources of hope (meaning in life, reconciliation, hope for finishing important goals—i.e., not cure-focused)
- Increases satisfaction with care
- **Is a patient need**

Puchalski, 2014



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Formulation of an Assessment and Treatment Plan

Recommendations:

- Screen, history and assess
- All health care professionals should do spiritual screening
- Clinicians who refer should do spiritual histories and develop appropriate treatment plans working with tribal elders and spiritual leaders
- Identify spiritual distress
- Treatment plans that include psychosocial and spiritual support with behavioral health and traditional healers
- Support/encourage in expression of needs and beliefs
- Provide patient navigation and referred provider education support

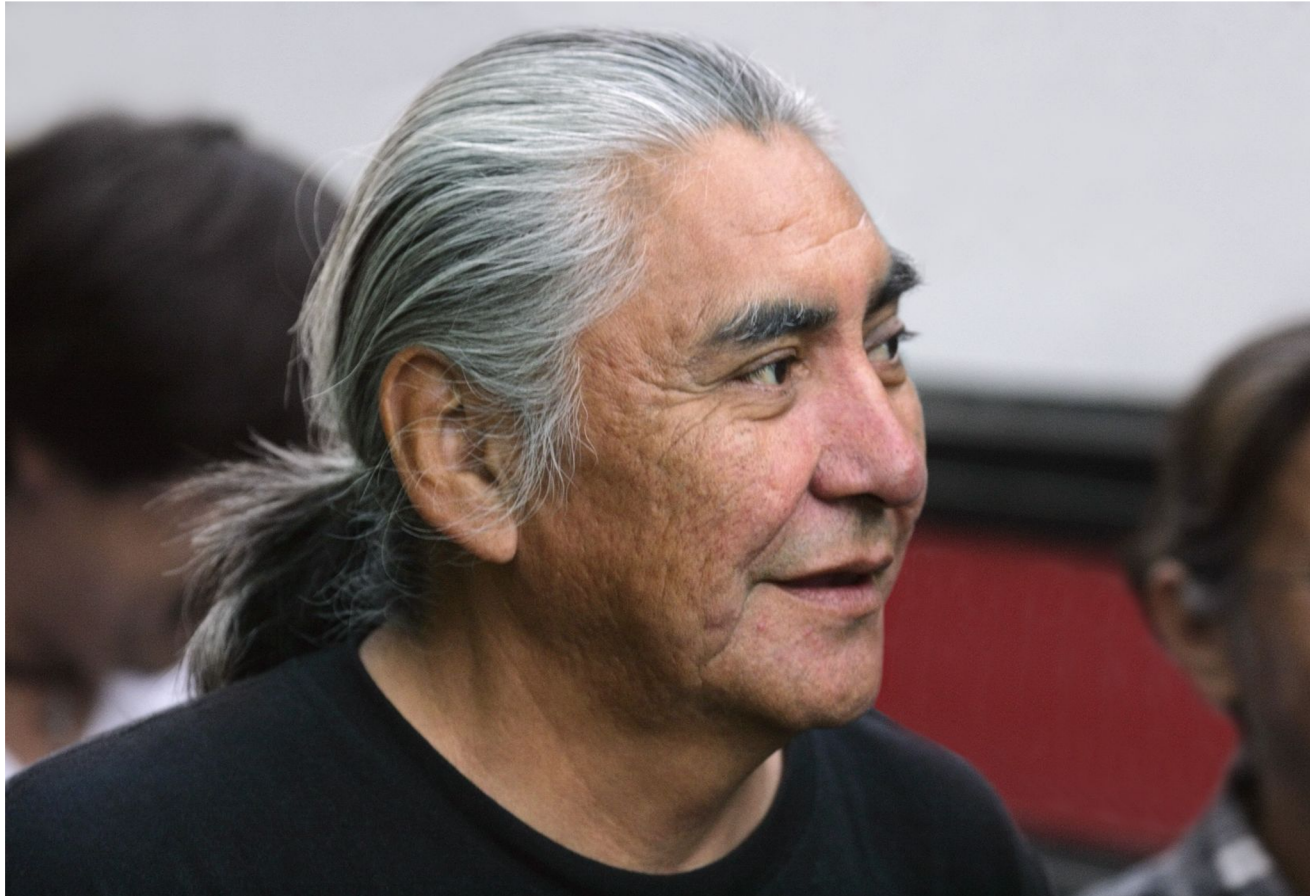
Puchalski, 2014



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Rehabilitation



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Rehabilitation for Cancer Survivors

- Rehabilitation can significantly improve:
 - Physical outcomes
 - Psychological outcomes
 - Quality of life outcomes
- Survivors have unmet needs related to rehabilitation
- Rehabilitation can be incorporated across the care continuum, even at diagnosis (prehabilitation)
- Patients should be referred to licensed/board certified rehabilitation health care professionals

Silver et al., 2013
Silver, 2014



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Smoking Cessation



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Smoking Cessation for Cancer Survivors

- Quitting smoking has many benefits for cancer patients:
 - Makes cancer treatment more effective
 - Reduces the painful side effects of treatment
 - Reduces the risks of cancer recurrence
- Patients may utilize a variety of resources:
 - Tribal smoking cessation specialists
 - Nicotine replacement therapy
 - Home visiting program
 - Michigan Tobacco Quitline 1-800-QUIT-NOW



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Survivorship Guidelines



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Cancer Survivorship Clinical Practice Guidelines

National Comprehensive Cancer Network

- **By Topic:**
 - Anxiety and depression
 - Cognitive function
 - Exercise
 - Fatigue
 - Immunizations and infections
 - Pain
 - Sexual function (female/male)
 - Sleep disorders

American Society of Clinical Oncology

- **By Topic:**
 - Neuropathy
 - Fatigue
 - Anxiety and depression
 - Fertility preservation
 - Breast cancer survivorship care guideline (ACS/ASCO)

American Cancer Society Survivorship Care Guidelines for Primary Care Providers

- **By Topic:**
 - Holistic:
 - Surveillance
 - Screening
 - Long-term and late effects
 - Health promotion
 - Breast (ACS/ASCO), colorectal, head and neck and prostate currently available



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American Cancer Society Cancer Survivorship Care Guidelines

Surveillance for Cancer Recurrence

Screening for Second Primary Cancers

Assessment and Management of Physical and Psychosocial Long-Term and Late Effects

Health Promotion

Care Coordination



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View the Guidelines

- Breast at bit.ly/BrCaCare
- Colorectal at bit.ly/acscolorc
- Head and Neck at bit.ly/acsheadneck
- Prostate at bit.ly/ACSPrCa



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Primary Care Providers' Role in Cancer Survivorship Care

- PCPs should play an active role in the care coordination of cancer survivors by:
 - Promoting healthy behaviors
 - Assisting in the surveillance for cancer recurrence and second primary cancers
 - Assessing and managing physical and psychosocial long-term and late effects
 - Clarifying care roles when needed with other members of the cancer treatment team



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Group work



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CANCER SURVIVORSHIP E-LEARNING SERIES FOR PRIMARY CARE PROVIDERS

www.gwccacademy.org

OVERVIEW

FACULTY

ACCREDITATION

REGISTER/TAKE COURSE

Primary care providers play a critical role in providing follow-up care for cancer survivors, including dealing with many of the physical, psychological, practical, informational and spiritual challenges after the completion of cancer treatment.

Clinicians can learn about caring for survivors of adult-onset cancers through a series of ten enduring online educational modules:

- Module 1: The Current State of Survivorship Care and the Role of Primary Care Providers
- Module 2: Late Effects of Cancer and its Treatments: Managing Comorbidities and Coordinating with Specialty Providers

COURSE SUMMARY

Course opens: 04/15/2020

Course expires: 12/31/2025

Rating: ★★★★★

E-Learning Series: Module Topics

- Each module includes:
 - Survivor interview
 - Narrated presentations
 - Pre/post assessments
 - List of resources
 - One hour CME/CNE per module



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Survivorship Resources

- National Cancer Survivorship Resource Center
www.cancer.org/survivorshipcenter
- Cancer Survivorship E-Learning Series for Primary Care Providers
www.gwccacademy.org
- ACS Prevention, Early Detection and Survivorship Guidelines
www.cancer.org/professionals



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Questions?

For questions about this presentation or the National Cancer Survivorship Resource Center Toolkit, contact cancercenter@gwu.edu.

Visit us at:

www.gwccacademy.org and
www.cancercontroltap.org



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Extra slides



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The Need for Survivorship Care

- Rapidly growing population of survivors
- Survivors experience unmet physical, psychosocial, practical and spiritual needs
- Inconsistent coordination of care and communication between primary care providers and oncologists
- Significant long-term and late effects
- Complexity of care, comorbid conditions

*American Cancer Society, 2014a
Smith et al., 2008*



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Case vignette #1

Ana is visiting you for her annual check up. She mentions that she finished breast cancer treatment recently and has not been back to see her oncologist since treatment ended six months ago. She says she is feeling really tired and just is not herself lately. She feels like she should be happy that they got the cancer out, but she has no energy and is self-conscious about intimacy. She has been taking it easy after treatment, because she has had some tingling in her feet and figures she should not be exercising too much after having cancer.



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Case vignette #2

Nelson comes to you, because he has been feeling flu-like symptoms. While you talk to him about getting a flu shot next year, you ask him how his health is doing overall. You know he is a colorectal cancer survivor about 7 years post-treatment. Nelson says he figures he is doing pretty well. He still has to frequently go to the bathroom at inconvenient moments, so he has cut back on work hours. He teeth have been hurting more and he feels tired a lot.



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Report out

- What can you do to encourage health promotion in your patient?
- What follow up should the patient have and with what provider?
- What symptoms is the patient at risk for? How should you help them manage potential long term and late effects of cancer treatment?
- What else do you need to know from other health care providers to manage your patient's health care going forward?



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