

Advancing Survivorship Care through Program Development

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Disclosures

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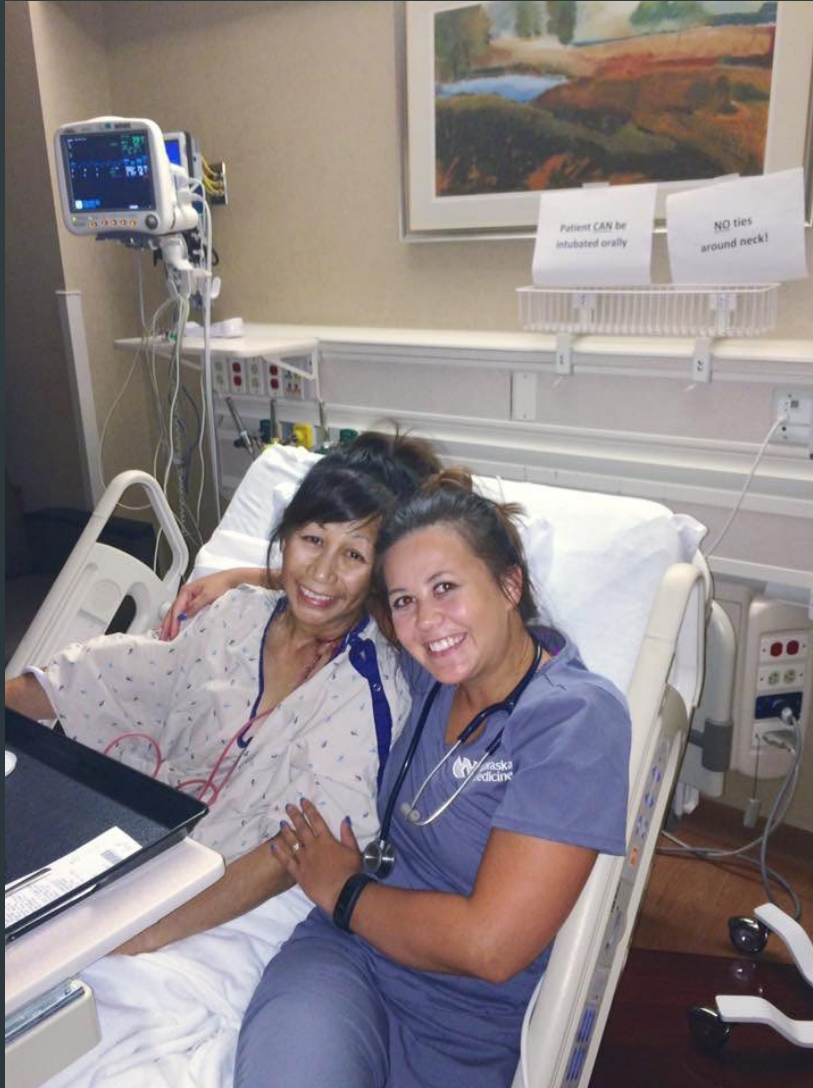
- None to declare



Objectives

- Discuss models of survivorship care to support the long-term follow-up of cancer survivors.
- Explore ideas to address special areas of survivorship care including fertility, post allogenic stem cell transplant care, and the transition of survivors of childhood cancer from pediatric to adult survivorship programs.
- Explain how to financially support a survivorship program.

Who is a Cancer Survivor?



A *survivor* is anyone living with a history of cancer – from the moment of diagnosis through the remainder of life.



What is Cancer Survivorship?

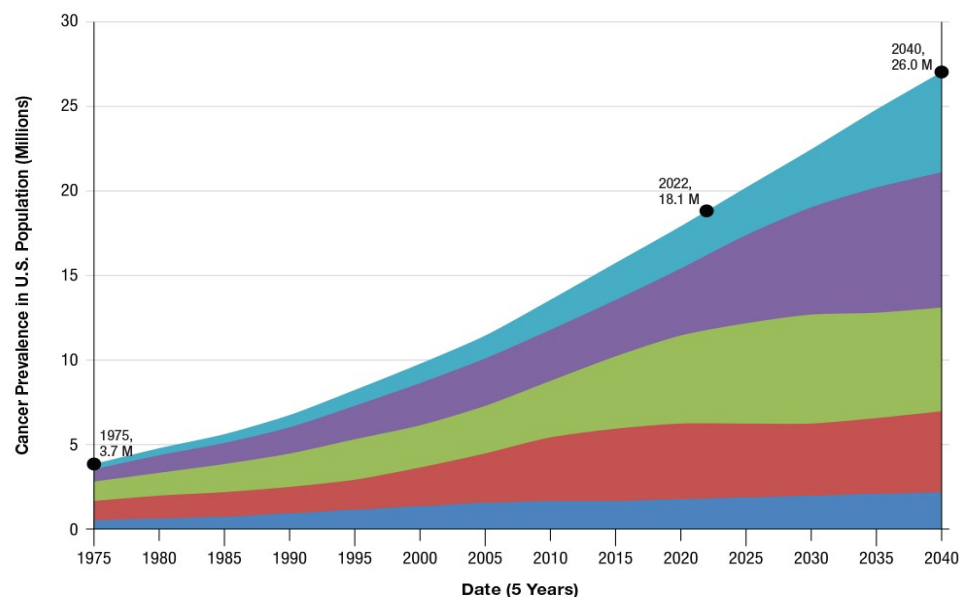




Why is Survivorship Important?



Cancer Prevalence and Projections in U.S. Population from 1975–2040



KEY

Age

■ <50 ■ 50-64 ■ 65-74 ■ 75-84 ■ 85+

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Miller KD, Nogueira L, Devasia T, Mariotto AB, Yabroff KR, Jemal A, Kramer J and Siegel RL. Cancer Treatment and Survivorship Statistics. *CA A Cancer J Clin.* 2022.



Survivorship Care Models



Risk-Stratified/ Personalized Care

Pending Crisis:

- Growing survivorship population
- Clinician shortages
- Clinician knowledge gaps
- Cost of care
- Lack of time

Stratified Care (one size does not fit all):

- Low Risk – self management with transition back to PCP
- Moderate Risk - a shared care model to briefly manage survivorship needs with PCP
- High Risk - complex case management where patients are followed by a multi-disciplinary team long term (oncologist, survivorship, and PCP)



Survivorship Models

Oncology Specialist Care	<ul style="list-style-type: none">+ Continuity of care- Not focused on late/long term effects or wellness; lack of time
Multidisciplinary Clinic	<ul style="list-style-type: none">+ Expertise in late/long term effects; multiple services in one location- Resource and time intensive; not needed by all survivors
Disease Specific Survivorship Clinic	<ul style="list-style-type: none">+ Expertise in one particular area; simple to pilot service and apply guidelines- Limited to survivor populations with large numbers
General Survivorship Clinic	<ul style="list-style-type: none">+ Provides survivorship services for all groups; financially more efficient- Difficult to have expertise in one clinic across all survivor groups
Consultative Survivorship Clinic	<ul style="list-style-type: none">+ Continuity oncologist, fewer resources, provides post treatment plan- One time visit with no follow up; limited time; requires a billing provider
Community / Shared care with Primary Care	<ul style="list-style-type: none">+ Focus is on wellness and co-morbid conditions; promotes independence- Limited knowledge on late/long term effects; roles not clearly delineated



Mixed Model Example

Nebraska Medicine Survivorship Program

General
Survivorship
Clinic

Disease
Based
(Thyroid
and Gyn
Onc)

Allogeneic
PSCT Long
Term Follow
Up Clinic

Adult
Survivors of
Childhood
Cancer
Clinic



Survivorship Care Plan

- Key survivorship component
- Road map for post-treatment care
- Tool for care coordination and communication



Utilize SCPs to Improve Coordination of Care



A pillar of survivorship care focuses on clean communication between oncology and primary care providers



Current guidelines are often vague and lack specificity as to what tests are needed and are inconsistent across professional societies



Vague recommendations lead to overuse and underuse of resources and can negatively impact the cost and quality of survivorship care



When survivorship care plans are given to PCPs and patients it can decrease ambiguity and increase adherence

Survivorship = Supportive Care Services



Nutrition

Psychiatry /
Psychology

Physical /
Occupational
Therapy

Support
Groups

Social Work

Smoking
Cessation

Genetic
Testing

Oncofertility

Massage

Acupuncture

Mindfulness

Yoga



Special Areas of Survivorship



Oncofertility

Oncofertility





Oncofertility Significance

Distress Regarding Infertility Risk

Adverse Health Outcomes

Reduced QOL

Oncofertility Significance – Areas to Improve

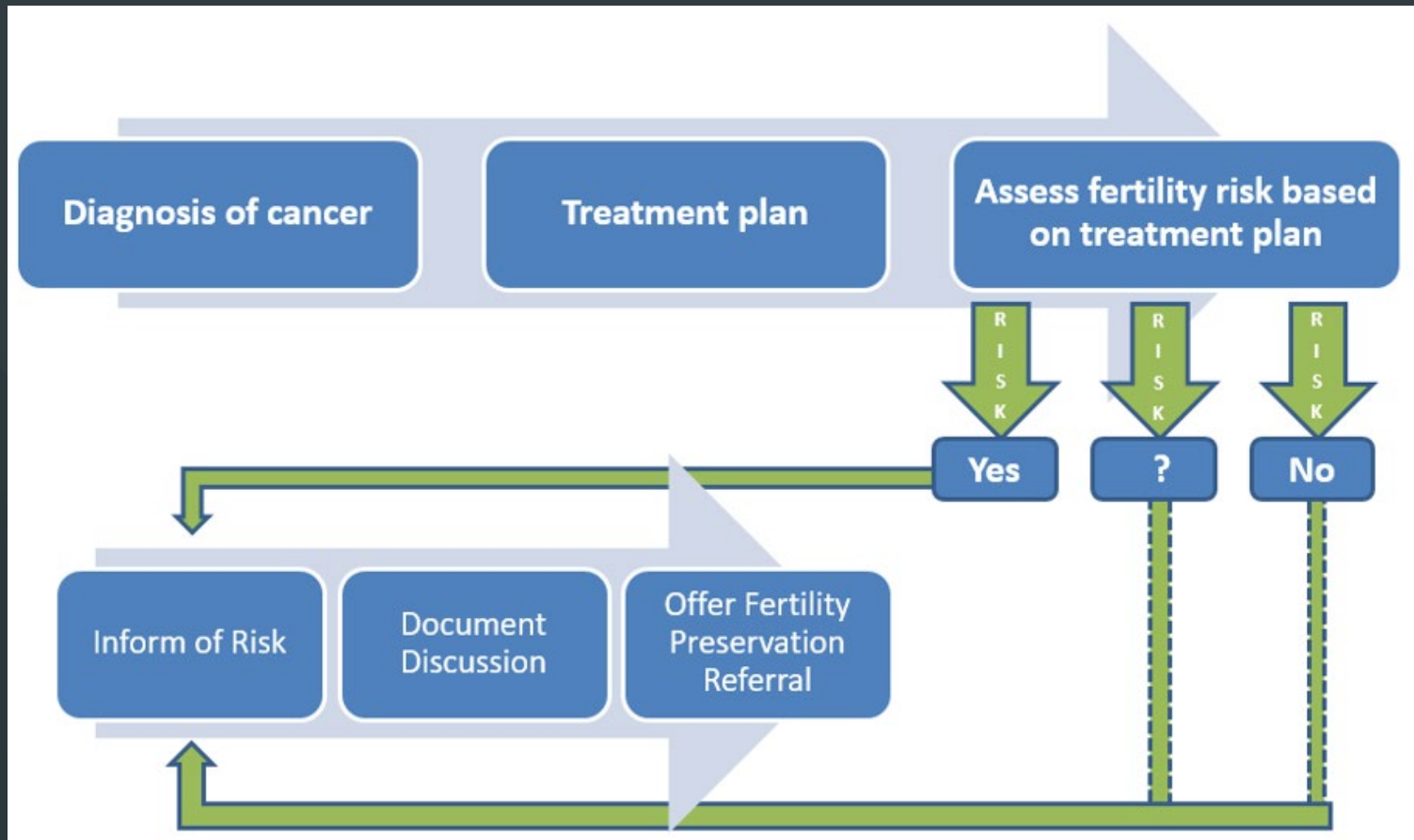


Documentation

Provider Knowledge
– Infertility
Risk/Options for
Fertility preservation

Patient/Provider
Education materials

Coordination of
Referrals/Financial
assistance





Best Practices to Implement

Discuss	Discuss infertility risk and fertility preservation with all pts ages 15-45, Parent/Guardian if younger
Refer	Refer all interested and ambivalent patients
Address	Address fertility preservation before treatment starts
Document	Document discussion
Answer	Answer basic questions about impact on cancer treatment
Refer	Refer to psychosocial providers if they experience distress
Encourage	Encourage registries and clinical trials



Adult Survivors of Childhood Cancer



Two Types of Transition:

Acute Care to Long Term Follow Up

- Varies between institutions
- Focus on late effect screenings and health promotion
- May cause mixed emotions (not seeing staff as frequently)

Pediatric Care to Adult Care

- Occurs as adolescents and young adults “age out” of pediatric healthcare system
- Focus on preparation of survivor and family to assist in successful transition
- May cause mixed emotions while transitioning from familiar to unfamiliar setting with new providers



Areas for Improvement

Adolescent and young adult (AYA) childhood cancer survivors (CCS) should be empowered to continue their survivor-focused care as they transition into adult medicine.

However, the majority of AYA-aged survivors (~60%):

- Have deficient health-related knowledge
- Not engaged in recommended health promotion and screening practices that could improve their long-term outcomes
- Become lost to follow up around the age of typical transition to adulthood

Adult Survivors of Childhood Cancer Clinic



Children's
Hospital

Nebraska
Medicine
Pediatric BMT

Self Referral



Themes of Transition Clinic

Emphasize risk-based screening and health promotion

Bridge the knowledge deficit of primary care providers on screening guidelines and health risks

Reinforce the importance of ongoing follow up for asymptomatic survivors

Create a plan and provides ongoing education

Provide up to date resources for survivors as they mature

Discussion of infertility risk, assessment, and available options after treatment

Facilitate survivorship research



Post Allogeneic Transplant Survivors

Post Allogeneic Transplant Survivors



Increasing Number of Transplant Survivors in the US

- ~ 108,900 survivors in 2010
- ~ 240,000 survivors in 2020
- ~>300,000 survivors by 2030

However, many survivors develop chronic health issues after transplant

40% of transplant survivors will develop severe health conditions 15 years after transplant

Life expectancy and quality of life of transplant survivors is less than the normal population

Common Late/Long Term Effects



<u>Adverse Effects</u>	<u>Risk Factors</u>
Cardiomyopathy	Pre-HSCT anthracyclines, chest radiation
Chronic kidney disease	High-dose methotrexate, calcineurin inhibitors, total body irradiation
Diabetes or impaired glucose	Total body irradiation, immunosuppressive therapy
Dyslipidemia	Total body irradiation, immunosuppressive therapy
GvHD	Allo-PSCT, mismatched donor
Endocrine complications	Pre-HSCT radiation to thyroid gland, pre-HSCT alkylating agents, total body irradiation, gonadal irradiation, busulfan
Hypertension	Total body irradiation, immunosuppressive therapy
Ocular complications	Cranial irradiation, total body irradiation, steroids, GvHD
Osteopenia or osteoporosis	Calcineurin inhibitors, corticosteroids, total body irradiation, prolonged hospitalization
Pulmonary dysfunction	Chest radiation, total body irradiation, GvHD
Sarcopenic obesity	Steroids, chemotherapy
Secondary malignancies	Pre-HSCT radiation therapy, total body irradiation, immunosuppressive therapy, GvHD, oncogenic viruses, prolonged immunosuppression

Utilize Survivorship to Improve Quality of Life



Yearly visit with survivorship to address quality of life issues

Fatigue / Sleep
Nutrition / Exercise
Fear of recurrence /
Depression / Anxiety

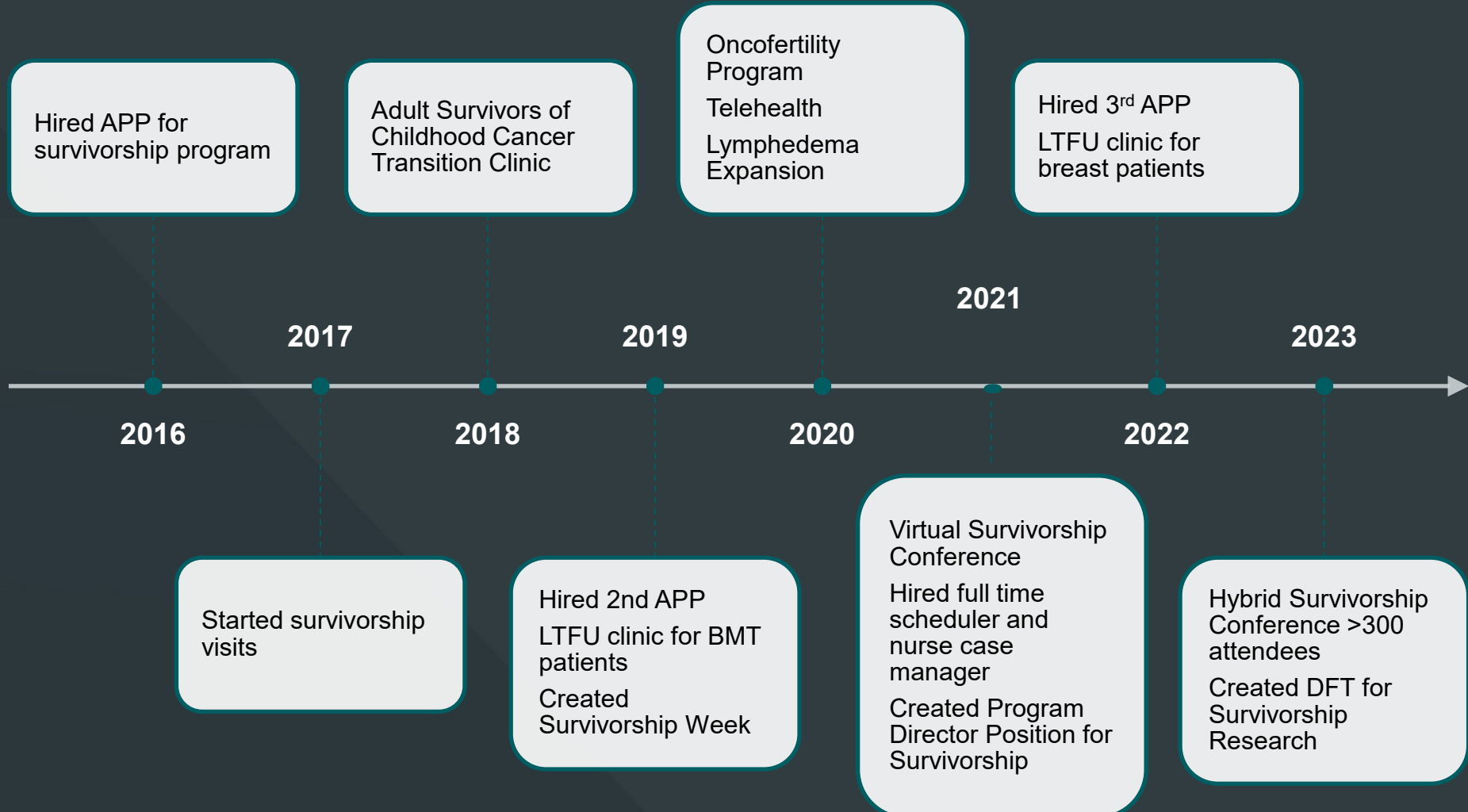


Allows oncologist to focus on cancer treatment
Patients get dedicated visits to address late/long term effects and health promotion



Financial Support for a Survivorship Program

Cancer Survivorship Program Timeline



Business Plan



Reimbursement

- Professional Fees
- Facility Fees
- Downstream analysis

Grants

Philanthropy

Increase new visits for oncologists

APP independent clinics





Stakeholder Involvement

Physician Champions

- Medical Director gives survivorship report at monthly division meeting

Administrative Leadership

- Regular meetings to discuss strategic planning

Cancer Committee

- Key member, contributes to quality improvement

Marketing/Outreach

- Social media, magazines, mailers, flyers



Infrastructure/Resources

Scheduler

Nurse / Patient Navigator

Advanced Practice Providers

Clarity on role

IT



Education / Guidelines



CANCER SURVIVORSHIP E-LEARNING SERIES FOR PRIMARY CARE PROVIDERS



National Comprehensive Cancer Network®

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Survivorship

Version 1.2021 — February 24, 2021

NCCN.org

NCCN Guidelines for Patients® available at www.nccn.org/patients

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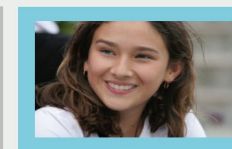
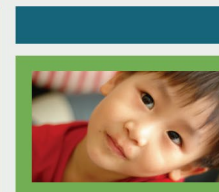
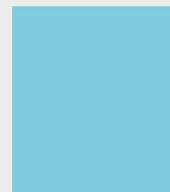
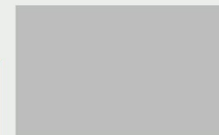
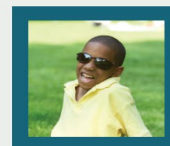
CHILDREN'S ONCOLOGY GROUP

The world's childhood cancer experts

Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent, and Young Adult Cancers

Version 5.0 - October 2018



Website: www.survivorshipguidelines.org
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Cancer Survivorship Research

Laura Tenner MD MPH



Evidence Gaps in Cancer Survivorship Care: A Report From the 2019 National Cancer Institute Cancer Survivorship Workshop

Identify evidence gaps and research priorities pertaining to cancer survivorship

Identified evidence gaps and next steps across the areas including:

- the need to understand and address disparities among cancer survivors,
- to conduct longitudinal studies as well as longer-term (>5 years postdiagnosis) follow-up studies,
- to leverage existing data,
- and to incorporate implementation science strategies to translate findings into practice



NCI Survivorship Workshop

Gaps in knowledge include:

- understanding recurrence risk in different subgroups of the cancer survivor population,
 - including those defined by age, race or ethnicity, immigrant status, socioeconomic status, sexual identity, and rurality
- and improving the recruitment of diverse participants to relevant observational studies and clinical trials examining surveillance

Many survivors should be getting sex and age-appropriate cancer screenings and general health preventive care, but how this testing should be integrated or prioritized relative to surveillance for recurrence or treatment related surveillance guidelines is unknown.



NCI Survivorship Workshop

Highlighted Topics for Study

- Improved Surveillance
- Management of Long-Term and Late Effects
 - Physical
 - Psychosocial
- Health Promotion
- Care Coordination
- Financial Impact



NCI Survivorship Workshop

Strategies and approaches that engage implementation science are vital

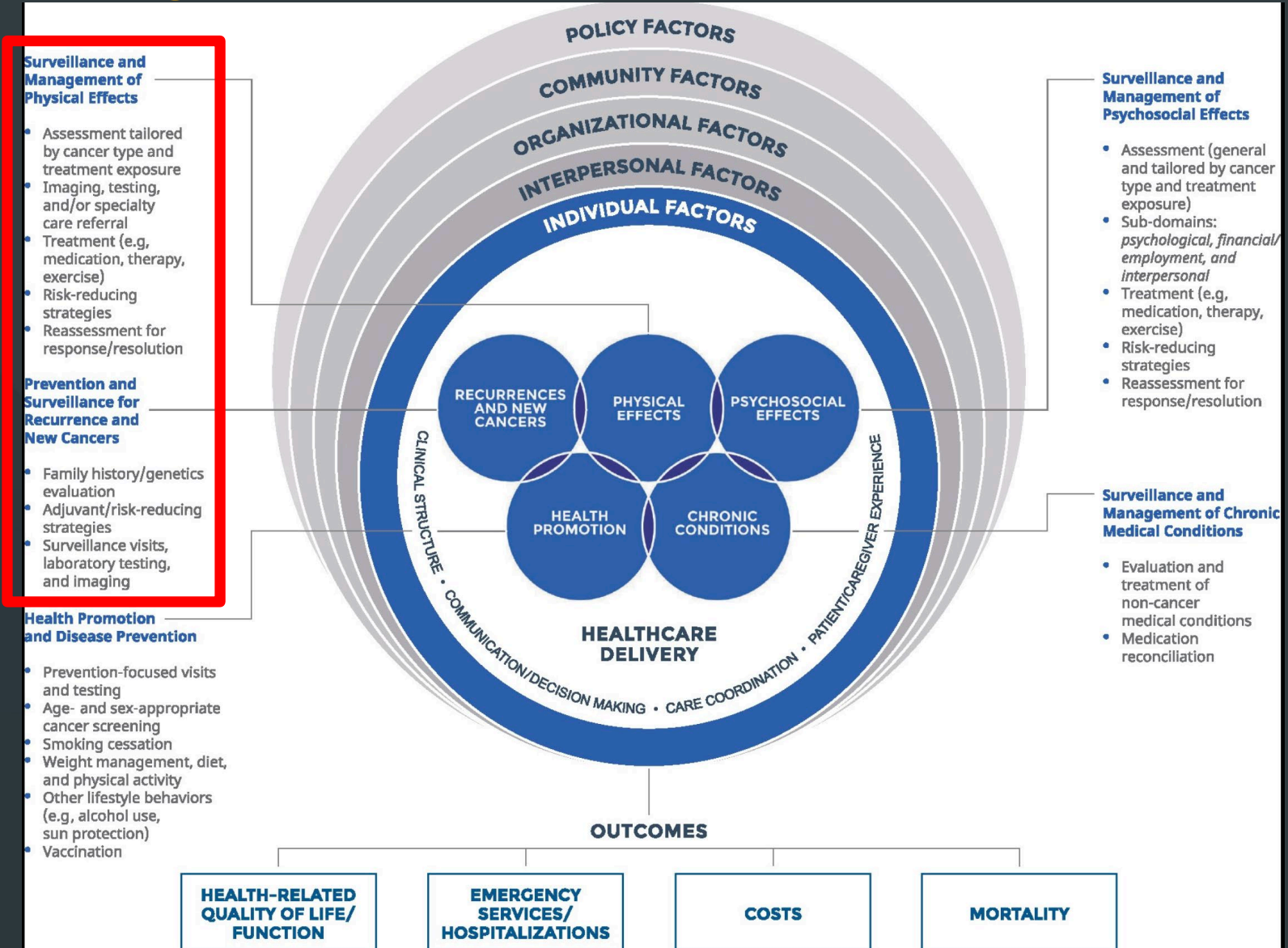
- Expanding existing data resources—
 - by leveraging big data,
 - exploring novel data linkages,
 - building data infrastructure,
 - establishing common data elements,
 - or incorporating PROs
 - and developing novel analytic methods



Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research, and Policy

Larissa Nekhlyudov, Michelle A Mollica, Paul B Jacobsen, Deborah K Mayer, Lawrence N Shulman, Ann M Geiger, Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research, and Policy, *JNCI: Journal of the National Cancer Institute*, Volume 111, Issue 11, November 2019, Pages 1120–1130, <https://doi.org/10.1093/jnci/djz089>

Cancer Survivorship Care Quality Framework



Quality Cancer Survivorship Framework



- Most commonly proposed measures were of physical and psychosocial effects and health promotion
- Measures of chronic medical conditions, care coordination, and health-care delivery structure were rare
- Outcomes such as costs, mortality, and adverse health-care utilization were less frequently measured than health-related quality of life.
- Patient-Centered Outcomes Research Institute grants mainly focused on surveillance for recurrences.

- Larissa Nekhlyudov, Michelle A Mollica, Paul B Jacobsen, Deborah K Mayer, Lawrence N Shulman, Ann M Geiger, Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research, and Policy, *JNCI: Journal of the National Cancer Institute*, Volume 111, Issue 11, November 2019, Pages 1120–1130, <https://doi.org/10.1093/jnci/djz089>



Solutions

- Targeted funding announcements addressing scientific gaps with designated and informed review panels
- Development of new patient-reported measures and those that may be ascertained using automated data
- Promotion of well-designed dissemination and implementation research for the sustained use of evidence-based strategies in clinical settings

• Larissa Nekhlyudov, Michelle A Mollica, Paul B Jacobsen, Deborah K Mayer, Lawrence N Shulman, Ann M Geiger, Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research, and Policy, *JNCI: Journal of the National Cancer Institute*, Volume 111, Issue 11, November 2019, Pages 1120–1130, <https://doi.org/10.1093/jnci/djz089>



Benefits to a Designated Survivorship Clinic

- Allows for a focused pool of patients that can be recruited for research studies who have finished active cancer therapy
- Allows for easier collection of EMR data
- Allows for easier implementation of PRO data in select populations
- Allows for a creation of a Diseased Focused Team (DFT)



Diseased Focused Teams

Multidisciplinary groups of basic, translational, clinical, and population health investigators who collaborate on a specific cancer area in order to further the translation of discoveries through the pipeline towards interventional clinical trials.

Cancer Prevention and Control

Benefits:

- Avoids competing studies,
- Tracks population research study participant numbers for NCI,
- Collects publications and further funding for completed research
- Builds a community of like-minded researchers for increased collaborations

References / Resources



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Nebraska Medicine Survivorship Clinic

<https://nebraskamed.com/survivorship>

Office of Cancer Survivorship

<https://cancercontrol.cancer.gov/ocs/statistics#stats>

Cancer Survivorship E-Learning Series for Primary Care Providers

<https://smhs.gwu.edu/gwci/survivorship/ncsrc/elearning>

NCCN Survivorship Guidelines

https://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf

Children's Oncology Group (COG)

<https://childrensoncologygroup.org/index.php/survivorshipguidelines>

Questions?



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