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.

American Cancer Society (2019)
What is Cancer Survivorship?

- Prevention
- Intervention
- Surveillance
- Coordination
Why is Survivorship Important?

18.1 MILLION CANCER SURVIVORS

69% OF SURVIVORS HAVE LIVED 5+ YEARS SINCE DIAGNOSIS

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

REFERENCES
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

<table>
<thead>
<tr>
<th>Model</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Oncology Specialist Care</strong></td>
<td>+ Continuity of care</td>
<td>- Not focused on late/long term effects or wellness; lack of time</td>
</tr>
<tr>
<td><strong>Multidisciplinary Clinic</strong></td>
<td>+ Expertise in late/long term effects; multiple services in one location</td>
<td>- Resource and time intensive; not needed by all survivors</td>
</tr>
<tr>
<td><strong>Disease Specific Survivorship Clinic</strong></td>
<td>+ Expertise in one particular area; simple to pilot service and apply guidelines</td>
<td>- Limited to survivor populations with large numbers</td>
</tr>
<tr>
<td><strong>General Survivorship Clinic</strong></td>
<td>+ Provides survivorship services for all groups; financially more efficient</td>
<td>- Difficult to have expertise in one clinic across all survivor groups</td>
</tr>
<tr>
<td><strong>Consultative Survivorship Clinic</strong></td>
<td>+ Continuity oncologist, fewer resources, provides post treatment plan</td>
<td>- One time visit with no follow up; limited time; requires a billing provider</td>
</tr>
<tr>
<td><strong>Community / Shared care with Primary Care</strong></td>
<td>+ Focus is on wellness and co-morbid conditions; promotes independence</td>
<td>- Limited knowledge on late/long term effects; roles not clearly delineated</td>
</tr>
</tbody>
</table>
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

Treatment Summary + Follow-up Plan = Survivorship Care Plan
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

Oncology
Study of Cancer

Fertility
The ability to produce offspring

Balancing life preserving treatment with fertility preserving options
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

<table>
<thead>
<tr>
<th>Discuss</th>
<th>Discuss infertility risk and fertility preservation with all pts ages 15-45, Parent/Guardian if younger</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refer</td>
<td>Refer all interested and ambivalent patients</td>
</tr>
<tr>
<td>Address</td>
<td>Address fertility preservation before treatment starts</td>
</tr>
<tr>
<td>Document</td>
<td>Document discussion</td>
</tr>
<tr>
<td>Answer</td>
<td>Answer basic questions about impact on cancer treatment</td>
</tr>
<tr>
<td>Refer</td>
<td>Refer to psychosocial providers if they experience distress</td>
</tr>
<tr>
<td>Encourage</td>
<td>Encourage registries and clinical trials</td>
</tr>
</tbody>
</table>
Adult Survivors of Childhood Cancer
## Two Types of Transition:

<table>
<thead>
<tr>
<th>Acute Care to Long Term Follow Up</th>
<th>Pediatric Care to Adult Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Varies between institutions</td>
<td>• Occurs as adolescents and young adults “age out” of pediatric healthcare system</td>
</tr>
<tr>
<td>• Focus on late effect screenings and health promotion</td>
<td>• Focus on preparation of survivor and family to assist in successful transition</td>
</tr>
<tr>
<td>• May cause mixed emotions (not seeing staff as frequently)</td>
<td>• May cause mixed emotions while transitioning from familiar to unfamiliar setting with new providers</td>
</tr>
</tbody>
</table>
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

Three ways of entry into the 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

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

- **2016**: Hired APP for survivorship program
- **2017**: Started survivorship visits
- **2018**: Adult Survivors of Childhood Cancer Transition Clinic
- **2019**: Oncofertility Program, Telehealth, Lymphedema Expansion
- **2020**: Hired 2nd APP LTFU clinic for BMT patients, Created Survivorship Week
- **2021**: Virtual Survivorship Conference, Hired full time scheduler and nurse case manager, Created Program Director Position for Survivorship
- **2022**: Hired 3rd APP LTFU clinic for breast patients
- **2023**: Hybrid Survivorship Conference >300 attendees, Created DFT for Survivorship Research
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
CANCER SURVIVORSHIP E-LEARNING SERIES FOR PRIMARY CARE PROVIDERS

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

Continue
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
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.

Lisa Gallicchio, Emily Tonorezos, Janet S de Moor, Joanne Elena, Margaret Farrell, Paige Green, Sandra A Mitchell, Michelle A Mollica, Frank Perna, Nicole Gottlieb Saiontz, Li Zhu, Julia Rowland, Deborah K Mayer, Evidence Gaps in Cancer Survivorship Care: A Report From the 2019 National Cancer Institute Cancer Survivorship Workshop. JNCI: Journal of the National Cancer Institute, Volume 113, Issue 9, September 2021, Pages 1136–1142, https://doi.org/10.1093/jnci/djab049
NCI Survivorship Workshop

Highlighted Topics for Study

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

Lisa Gallicchio, Emily Tonorezos, Janet S de Moor, Joanne Elena, Margaret Farrell, Paige Green, Sandra A Mitchell, Michelle A Mollica, Frank Perna, Nicole Gottlieb Saiontz, Li Zhu, Julia Rowland, Deborah K Mayer, Evidence Gaps in Cancer Survivorship Care: A Report From the 2019 National Cancer Institute Cancer Survivorship Workshop, *JNCI: Journal of the National Cancer Institute*, Volume 113, Issue 9, September 2021, Pages 1136-1142, [https://doi.org/10.1093/jnci/djab049](https://doi.org/10.1093/jnci/djab049)
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

Cancer Survivorship Care Quality Framework

- **Surveillance and Management of Physical Effects**
  - Assessment tailored by cancer type and treatment exposure
  - Imaging, testing, and/or specialty care referral
  - Treatment (e.g., medication, therapy, exercise)
  - Risk-reducing strategies
  - Reassessment for response/resolution

- **Prevention and Surveillance for Recurrence and New Cancers**
  - Family history/genetics evaluation
  - Adjuvant/risk-reducing strategies
  - Surveillance visits, laboratory testing, and imaging

- **Health Promotion and Disease Prevention**
  - Prevention-focused visits and testing
  - Age- and sex-appropriate cancer screening
  - Smoking cessation
  - Weight management, diet, and physical activity
  - Other lifestyle behaviors (e.g., alcohol use, sun protection)
  - Vaccination

- **Surveillance and Management of Psychosocial Effects**
  - Assessment (general and tailored by cancer type and treatment exposure)
  - Sub-domains: psychological, financial/employment, and interpersonal
  - Treatment (e.g., medication, therapy, exercise)
  - Risk-reducing strategies
  - Reassessment for response/resolution

- **Surveillance and Management of Chronic Medical Conditions**
  - Evaluation and treatment of non-cancer medical conditions
  - Medication reconciliation

- **Surveillance and Management of Cost Outcomes**
  - Evaluation and treatment of non-cost outcomes
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.

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


**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**

**Children’s Oncology Group (COG)**
https://childrensoncologygroup.org/index.php/survivorshipguidelines
Questions?

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