Enhancing Quality of Life for Cancer Survivors in South Dakota

Outcomes from the South Dakota Cancer Survivorship Program
The South Dakota Survivorship Program was funded through cooperative agreement number DP006114 to the South Dakota Department of Health funded by the Centers for Disease Control and Prevention. The contents of this presentation are solely the responsibility of the presenters and do not necessarily represent the official views of the Centers for Disease Control and Prevention.
PROGRAM OVERVIEW

Presenter: Lexi Pugsley, MS, RN
Background

- Cancer survivor refers to any person with a history of cancer, from the time of diagnosis through the remainder of their life
- Cancer incidence remains high
  - 1.7 million new cancer cases diagnosed in the US in 2018
  - 5,100 new cancer cases diagnosed in SD in 2018
- Prevalence of cancer survivors in the US continues to increase
  - 15.5 million cancer survivors in the US
  - 39,330 cancer survivors in SD
- Advancements in cancer care and an aging population are leading to a continued increase in survival rates
- Nearly 12% of South Dakotans report having cancer at one point in their lifetime
Project Period: 9/30/15-9/29/18

Clinical Partners:

• Avera Cancer Institutes: Aberdeen, Mitchell, Sioux Falls, and Yankton, Sanford Cancer Center, Urology Specialists

Focus Areas:

• Patient Navigation
• Surveillance
• Survivorship Care Plans
• Health Status and Knowledge of Cancer Survivors
• Healthcare Provider Knowledge
• Dissemination of Evidence via Publications
Patient Navigation

- Tobacco Cessation Referrals: 21 (66% of eligible survivors) in 2016, 39 (85% of eligible survivors) in 2017
- Nutrition/Physical Activity Referrals: 232 (85% of eligible survivors) in 2016, 353 (85% of eligible survivors) in 2017
- CRC Screening Referrals: 33 (65% of eligible survivors) in 2016, 62 (85% of eligible survivors) in 2017
**SOUTH DAKOTA BRFSS SURVEILLANCE BRIEF: CANCER SURVIVORSHIP**

**Background:**
The American Cancer Society (ACS) estimates there are 18.2 million cancer survivors living in the U.S. Since the 1990s, the incidence of cancer cases has been increasing with diagnoses of new cases increasing by almost 50%. Over time, cancer care has improved, increasing the proportion of people who are cured of their cancer. Surveillance is essential to monitoring the health of cancer survivors and to informing future research and programs. Over the past 5 years, survival rates have improved for most cancer types. Surveillance is critical to identify trends in cancer incidence, survival, and health outcomes and to inform evidence-based policy and program implementation.

**Methods:**
- The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) has conducted a comprehensive cancer surveillance program to monitor cancer incidence and survival in the U.S. This system is based on population-based surveillance data from SEER registries, which are Federal and state cancer registries that have been designated by NCI to conduct surveillance for certain cancers. Surveillance data provides a snapshot of the cancer burden in the U.S. and highlights areas where improvements are needed. The SEER Program uses cancer registration data to monitor cancer incidence, survival, and health outcomes in the U.S.
- The Surveillance, Epidemiology, and End Results (SEER)-based Surveillance, Research, and End Results (SURE) Program is a national surveillance system that collects comprehensive data on cancer incidence, survival, and health outcomes. SURE data are used to monitor the incidence and survival of cancer in the U.S. and to identify trends in cancer incidence, survival, and health outcomes.

**Results:**
- In 2019, 12.9% of South Dakota adults reported having cancer in their lifetime, including 5.9% who reported having cancer in 2019.
- In 2019, 7.6% of South Dakota adults reported having cancer in their lifetime, including 3.0% who reported having cancer in 2019.

**Table 1: Cancer Types Reported**

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain</td>
<td>1.6%</td>
<td>1.7%</td>
</tr>
<tr>
<td>Breast</td>
<td>11.4%</td>
<td>11.5%</td>
</tr>
<tr>
<td>Colorectal</td>
<td>5.6%</td>
<td>5.7%</td>
</tr>
<tr>
<td>Cervix</td>
<td>2.7%</td>
<td>2.8%</td>
</tr>
<tr>
<td>Lung</td>
<td>9.0%</td>
<td>9.1%</td>
</tr>
<tr>
<td>Melanoma</td>
<td>0.9%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Rectal</td>
<td>5.1%</td>
<td>5.2%</td>
</tr>
<tr>
<td>Stomach</td>
<td>2.4%</td>
<td>2.5%</td>
</tr>
</tbody>
</table>

**Figure 1:** Surveillance for cancer incidence, survival, and health outcomes is critical to understanding the burden of cancer in the U.S. and identifying areas where improvements are needed. The SEER Program uses cancer registration data to monitor cancer incidence, survival, and health outcomes in the U.S. and provides a snapshot of the cancer burden in the U.S. and highlights areas where improvements are needed. The SEER Program uses cancer registration data to monitor cancer incidence, survival, and health outcomes in the U.S. and provides a snapshot of the cancer burden in the U.S. and highlights areas where improvements are needed.

Available at: [https://www.cancersd.com/evaluation-and-outcomes/](https://www.cancersd.com/evaluation-and-outcomes/)
Survivorship Care Plan Content

- **Treatment Summary**
  - Contact information for providers and centers who administered the treatment
  - Basic diagnostic and staging information
  - Information on surgery, radiation therapy, systemic therapy (both chemotherapcy and biologic therapies), and ongoing significant toxicities, including dates

- **Follow-Up Care Plan**
  - Surveillance plan to detect recurrence and late adverse effects
  - Interventions to manage ongoing problems resulting from the cancer and its treatment
  - Age- and sex-appropriate health care, including cancer screening
  - General health promotion
SCP Requirements: CoC Standard 3.3

- Must contain input from the principal physician and oncology care team who coordinated treatment, as well as input from the patient’s other care providers.
- The survivorship care plan is given and discussed with the patient upon completion of active, curative treatment and recorded in the patient medical record.
- The timing of delivery of the SCP is within one year of the diagnosis of cancer and no later than six months after completion of adjuvant therapy (other than long-term hormonal therapy).
- Providing the SCP by mail, electronically, or through a patient portal without discussion with the patient does not meet the standard.
SCP Eligibility

- In general, cancer survivors meeting the following criteria are considered eligible for receipt of a SCP
  a) diagnosed and/or received first course of treatment, all or in part, at one of the participating locations
  b) cancer stage I, II, or III (plus ductal carcinoma in situ for centers accredited by the National Accreditation Program for Breast Centers)
  c) treated with curative intent for initial cancer occurrence
  d) completed active therapy
Barriers to SCP Implementation

- The substantial time required to complete an SCP
- Inadequate reimbursement for the time and resources required to complete the SCP
- Challenges in coordinating care among providers and between providers and survivors
- Incomplete penetration of EHR systems in the marketplace that can facilitate SCP completion
Project Implementation Efforts

- Adoption of SCP policies
- Patient navigation
- Professional education, certification, and competency adoption
- Workflow enhancements
- Implement EHR and reporting enhancements
- Focus on care coordination and PCP collaboration
- Test promising models and share best practices
- Focus on sustainable practices
Survivorship Care Plans

CoC Standards:
• End of 2015: ≥10% ✓
• End of 2016: ≥25% ✓
• End of 2017 and on: ≥50% ✓
Healthcare Provider Knowledge

**In-Person**
- Cancer Survivorship Training - May 2016
- Motivational Interviewing - June 2018

**Webinars**
- Patient Navigation in Oncology
- ACS Survivorship Webinar Series
- SD QuitLine and Tobacco Assessment and Referral
- Incorporating Cancer Survivorship Into Primary Care

**Online Training**
- Cancer Survivorship E-Learning Series for Primary Care Providers
“Our greatest accomplishment has been the standardization of survivorship care planning services across a geographically diverse health system.”

“Our greatest accomplishment has been the extension of survivorship care planning services to underrepresented and underserved populations.”

“Being able to implement a dedicated GU Navigator has been a huge accomplishment. This has allowed us to reach a population we were previously unable to connect with, and has increased collaboration with the urology group and oncology group as a whole.”
Cancer Survivorship Efforts Moving Forward

SD Cancer Coalition - Cancer Survivorship Task Force

Topics for consideration:
- Survivorship Care Plan (SCP) Provision
- Professional Development/Provider Referrals
  - Primary Care Providers and SCPs
  - Tobacco Cessation Referrals for Cancer Survivors
  - Physical Activity Referrals for Cancer Survivors
  - Community/Clinical Resource (Better Choices, Better Health, etc.) Referrals for Cancer Survivors
- Caregivers
- Coping
Dissemination of Evidence via Publications

Presenter: Jenna Cowan, BS
Implementation of Survivorship Care Plans at Three Health System-Based Cancer Centers in a Rural State

September 2016

White Papers
Available at: https://www.cancersd.com/evaluation-and-outcomes/
Conducted structured interviews with three health systems (representing six cancer treatment center sites)

Gained insights to how each health system elected to design and employ survivorship care plans
  • SCP development
  • SCP creation and delivery
  • Successes and effective strategies
  • Challenges and support needed

Framework for Implementation
  • Build a foundation
  • Gather resources
  • Review the evidence
  • Elicit input
  • Implement in stages
<table>
<thead>
<tr>
<th>Interview Questions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did you develop the templates for the survivorship care plan?</td>
</tr>
<tr>
<td>How has the process evolved since you initiated the survivorship care plan?</td>
</tr>
<tr>
<td>Describe how a patient is identified and then scheduled for the survivorship care plan appointment.</td>
</tr>
<tr>
<td>What is your current process for inputting information into the survivorship care plan template?</td>
</tr>
<tr>
<td>Describe how a patient receives the survivorship care plan.</td>
</tr>
<tr>
<td>How do you share the survivorship care plan with the patient’s primary provider?</td>
</tr>
<tr>
<td>What have you found to be the most challenging aspects of the process of developing, populating, delivering, and then sharing the survivorship care plan?</td>
</tr>
<tr>
<td>Have you witnessed any evidence of how the survivorship care plan has resulted in better patient care or outcomes?</td>
</tr>
<tr>
<td>Is there anything else that you think would be helpful for us to know as we review your process for survivorship care plans?</td>
</tr>
</tbody>
</table>
Conducted structured interviews with three health systems (representing six cancer treatment center sites)

Gained insights to how each health system elected to design and employ survivorship care plans
- SCP development
- SCP creation and delivery
- Successes and effective strategies
- Challenges and support needed

Framework for Implementation
- Build a foundation
- Gather resources
- Review the evidence
- Elicit input
- Implement in stages
Avera Cancer Institute
Navigation Center

Expanding cancer care services from prevention through survivorship
“Cancer is so complex. You have so many providers involved with one patient. You have so many medications and so many treatment regimens. You have such a high volume of people traveling from very rural areas to the cancer treatment center. All of the traditional burdens and barriers that fall into healthcare tend to be exacerbated for oncology.”
Commission on Cancer Standard 3.3

To maintain CoC accreditation in 2018, cancer programs must provide survivorship care plans to ≥50 percent of eligible patients who have completed treatment
With increases in the five-year survival rate, a focus on long-term survivorship care is of critical importance.

Survivorship care plans are recommended by the Institute of Medicine to help survivors make a successful transition to post-treatment cancer survivorship.

To maintain Commission on Cancer accreditation, cancer programs must provide survivorship care plans to ≥50 percent of eligible patients who have completed treatment.

Complications in identifying cancer survivors for survivorship care plan provision can arise when surgery privileges are granted to private providers outside of a health system.

This white paper highlights the unique collaboration of two individual health system cancer treatment centers with one auxiliary specialty center as they addressed provision of survivorship care plans in a hard to reach patient population of urological cancer survivors.
Collaboration for survivorship began in 2013.

Follow-up care is provided by the specialty center for surgery only patients. However, since the surgery took place at the health system, the patient is included in the denominator population for SCP provision to meet Standard 3.3.

Health system made a strategic decision to offer dedicated resources to provide care to this patient population that might not received any direct or additional services from the health system.

Hired a genitourinary oncology nurse navigator to provide patient navigation services, SCP creation and delivery.

Navigator has found success by having a physical presence at the specialty center, providing in-person delivery of the SCP.

GU Navigator position benefits both facilities.
Collaboration Model #2

- Collaboration for survivorship initiated in May 2017
- Through the health system’s involvement in the South Dakota Survivorship Program, funding was provided to support a GU oncology nurse navigator
- Gu Navigator role based at the Health System, SCP delivered by mail followed by a phone based visit
- Patients tend to be more open to discussing sensitive subjects over the phone rather than in person
- SCP provision supports both facilities mission and enhances the patient experience
- Exploring expansion of navigation services and SCP provision to patients of dermatology, thyroid, and other surgery-only patient populations.
Summary of Collaborations

- Survivorship collaborations with specialty providers can enhance care collaborations, as well as enhance the overall patient experience.

- Each health system developed a model of collaboration that fit with the unique needs and resources of their health system.

- Although the collaboration models vary in delivery methods, both models have received positive patient feedback, indicating that the service provides value regardless of the method of delivery, and is a good investment for the patient’s well-being.

- A healthy working relationship and clear communication between facilities is a necessity.

- Collaborations help support care coordination among facilities and provide a team approach to patient care.

- Same model could be used in other population gaps, such as dermatology patients, head and neck cancers, and breast cancer patient receiving surgery only from an outside provider.
Manuscript #1:

Cancer survivorship care plans: Processes, effective strategies, and challenges in a Northern Plains rural state

Mary J. Isaacson PhD, RN, CHPN, Polly A. Hulme PhD, CNP, RN, Jenna Cowan BS, Jennifer Kerkvliet MA, LPC, NCC
Manuscript #2:

Patient knowledge of cancer treatment history and follow-up care after receipt of a survivorship care plan

Manuscript #3:

Making the case for optimal use of survivorship care plans
Health Status and Knowledge of Cancer Survivors

Chamika Hawkins-Taylor, MHA, PhD
Study Objective:
To assess survivor perceived knowledge about their treatment history and follow-up care before and after SCP receipt.

Methods:
- Across six study locations, eligible survivors received a pre-SCP and 3-month post-SCP survey assessing perceived knowledge about disease, treatment, and follow-up care.
- Non-parametric tests assessed total knowledge change from pre- to post-SCP.

Results:
- N = 152 survivors who completed both the pre and post surveys.
- The sample was 80% female (45% breast cancer) and mean age, 60.5 years (sd=11.1).

Conclusion:
- SCPs can improve knowledge, and may equip survivors with the knowledge and skills required for self-management of the physical, psychological, and social needs that they may experience post treatment.
- SCP provision enhances the patient experience, impacting higher perceived knowledge for more informed management of follow-up care leading to better quality of life for cancer survivors.

Table: Change in survivor care knowledge after SCP

<table>
<thead>
<tr>
<th>Population</th>
<th>N</th>
<th>Pre-SCP</th>
<th>Post-SCP</th>
<th>Post - Pre</th>
<th>P-Valueb</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>152</td>
<td>25.5 ± 7.2</td>
<td>27.2 ± 4.3</td>
<td>1.7 ± 6.7</td>
<td>0.002</td>
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<tr>
<td>Restricted</td>
<td>127</td>
<td>24.6 ± 4.4</td>
<td>26.8 ± 4.0</td>
<td>2.3 ± 4.7</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

- a) The total population had complete data at pre- and post-program and the restricted population had disagree or agree response at pre-program.
- b) Wilcoxon Signed Rank test using post-SCP minus pre-SCP difference knowledge scores.
Making the Case for Optimal Use of Survivorship Care Plans

Study Aims:
1.) Examine the value of SCPs (survivorship plan use and health actions taken)
2.) Assess patient satisfaction with the SCP.

Methods:
Assessment of Outcome variables on pre and post survey related to:
1. Use of the SCP
2. Health Actions Taken
3. Satisfaction with follow-up information found on SCP.

Conclusion:
- Cancer survivors reporting SCP use were eleven times more likely to have taken a health action.
- Most frequently reported actions included getting regular checkups (53.9%), eating healthier (58.2%), being more physically active (52.9%) and scheduling preventive cancer screenings (51.9%).

Results:
- N = 189 survivors who completed both the pre and post surveys.
- The sample was 82% female (49% breast cancer).
- 60% of patients in Stage I or Stage II.

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search Information Online</td>
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<td></td>
</tr>
<tr>
<td>No</td>
<td>149</td>
<td>78.8%</td>
</tr>
<tr>
<td>Yes</td>
<td>40</td>
<td>21.2%</td>
</tr>
<tr>
<td>Ask Physician or Nurse About Concerns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>105</td>
<td>55.6%</td>
</tr>
<tr>
<td>Yes</td>
<td>84</td>
<td>44.4%</td>
</tr>
<tr>
<td>Inform About Symptoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>95</td>
<td>50.3%</td>
</tr>
<tr>
<td>Yes</td>
<td>94</td>
<td>49.7%</td>
</tr>
<tr>
<td>Find Referrals for Follow-Up Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>153</td>
<td>81.0%</td>
</tr>
<tr>
<td>Yes</td>
<td>36</td>
<td>19.0%</td>
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<tr>
<td>Shared with PCP</td>
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</tr>
<tr>
<td>No</td>
<td>160</td>
<td>84.7%</td>
</tr>
<tr>
<td>Yes</td>
<td>29</td>
<td>15.3%</td>
</tr>
<tr>
<td>Shared with Spouse or Partner</td>
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<td></td>
</tr>
<tr>
<td>No</td>
<td>90</td>
<td>47.6%</td>
</tr>
<tr>
<td>Yes</td>
<td>99</td>
<td>52.4%</td>
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<tr>
<td>Shared with Family Members at Risk</td>
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<td></td>
</tr>
<tr>
<td>No</td>
<td>137</td>
<td>72.5%</td>
</tr>
<tr>
<td>Yes</td>
<td>52</td>
<td>27.5%</td>
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</tbody>
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QUESTIONS?