FIRST YEAR EVALUATION OF THE SOUTH DAKOTA SURVIVORSHIP PROGRAM

CDC DP15-1501, Annual Report, Program Year 1

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Executive Summary:

First Year Outcomes of the South Dakota Survivorship Program

The South Dakota Survivorship Program (SDSP) aims to support cancer survivors through the expansion of cancer survivorship surveillance systems, facilitation of community/clinical linkages, education to survivors and healthcare providers on cancer survivor best practices and enhancement of the evidence related to survivorship practices.

Expanded survivorship services are needed in South Dakota, where 6.8% of the adult population are living with a history of cancer.²

The percent of SD cancer survivors who report fair or poor health status is more than double that of South Dakotans without a cancer diagnosis (28.5% vs. 12.3%).³ Cancer survivors may face numerous long-term and late effects from cancer treatment, including medical and psychological adversities. Furthermore, cancer survivors have an increased risk for additional cancers compared with persons without a cancer history.⁴

The SDSP provides the mentorship and funding needed to develop and/or expand cancer survivorship services throughout South Dakota, partnering with local cancer treatment centers and registries to promote statewide adoption of sustainable practice- and evidence-based survivorship activities.

The following program highlights, key findings, and recommendations included in this report are reflective of program activities conducted between September 30, 2015 and September 29, 2016.
Program Highlights

- Development of a free-standing patient navigation center, housed within one of the SDSP partner cancer treatment centers. The Navigation Center provides 24/7 patient navigation services through a call center and walk-in model.

- Inclusion of the full Cancer Survivorship Module in the 2016 Behavioral Risk Factor Surveillance System survey that will provide survivorship burden data to help plan and prioritize future survivorship initiatives and interventions.

- Navigator Network developed to foster collaboration among cancer partners and to provide education and training opportunities for cancer professionals statewide.

- Survivorship Care Plan (SCP) policies adopted at all five partner cancer treatment centers, ensuring that every oncology patient that has completed active therapy for a curative intent will be given a Survivorship Care Plan at the end of active treatment.

- White Paper released identifying a framework of the processes, challenges, and successes of implementation of Survivorship Care Plans in Health System-Based Cancer Treatment Centers.

Recommendations

1) Enhance the Navigator Network.

2) Support tobacco referral training in oncology.

3) Monitor and assess the capacity for SCP completion and delivery.
Cancer incidence continues to increase in the United States, with an estimated 1.6 billion new cases of cancer expected to be diagnosed in 2016. South Dakota is no exception, averaging nearly 4,000 new cancer cases diagnosed each year. Advancements in cancer care are leading to an increase in survival rates. The American Cancer Society (ACS) reports 40,130 cancer survivors, or 6.8% of adults residing in SD, are living with a history of cancer.

Through a 3-year cooperative agreement with the Centers for Disease Control and Prevention, the SD Department of Health (SD DOH) established the South Dakota Survivorship Program (SDSP) in September 2015. The SDSP aims to address the public health needs of cancer survivors in the state, to increase duration and quality of life.

The SD DOH contracted with South Dakota State University, Office of Nursing Research, to evaluate the implementation and outcomes of the SDSP. Objectives and strategies are outlined in the evaluation work plan to quantify the progress in six assessment areas, including:

1) Patient Navigation
2) Surveillance
3) Survivorship Care Plans
4) Health Status and Knowledge of Cancer Survivors
5) Healthcare Provider Knowledge
6) Dissemination of Evidence via Publications

The information in this evaluation report celebrates the first year accomplishments of the SDSP and its partner cancer treatment centers.

Program Goal: Statewide adoption of sustainable practice- and evidence-based survivorship activities, leading to increases in the duration and quality of life of cancer survivors.
The SDSP is in its inaugural year. As such, much effort was devoted to establishing the structure of the program, including program staffing and partnerships with cancer centers, as well as developing processes to implement evidence-based changes at the cancer centers, deliver healthcare provider training, and collect surveillance and outcome data.

At the onset of the SDSP, six cancer treatment centers from three of the largest health systems in SD agreed to partner with the program. Collectively, these cancer treatment centers serve most cancer patients residing in SD, making for an innovative partnership. Unfortunately, midway through Program Year 1, one of the three health systems elected to end their partnership with the SDSP. The SDSP moved forward with the five remaining partner cancer treatment centers and continues to serve a broad and diverse geographic area with the two partnering health systems.

A tremendous amount of planning has occurred in Program Year 1, which runs from September 30, 2015 to September 29, 2016, and many of the intended strategies are in process. Although these efforts have not been without challenges, at the close of Year 1, five cancer centers are partners, a navigator network exists, surveillance data collection is underway, and formalized survivorship care plan policies are established in all five cancer centers. The goal of the evaluation for this planning and early implementation year is to describe program components, identify effective implementation strategies and recommend adjustments to strategies to strengthen effectiveness.

An evaluation plan, developed early in Program Year 1, monitors implementation activities and verifies that the activities produce the identified short-term program outcomes, which include:

1) Increased knowledge of cancer survivor needs and gaps
2) Increased utilization of surveillance data to inform program planning
3) Increased use of survivorship care plans
4) Increased availability of patient navigation services
5) Increased survivor knowledge regarding preventative lifestyle behaviors, treatment, and follow-up care
6) Increased provider knowledge of guidelines pertaining to treatment of cancer survivors
South Dakota Cancer Treatment Centers partnering with the SDSP all had existing patient navigation programs at the beginning of Program Year 1. The existing programs primarily utilized professional navigators, with the exception of two lay American Cancer Society navigators. Most of the navigators in place at the facilities were Registered Nurses or Advance Practice Providers (Nurse Practitioners or Physician Assistants), with most providing site-specific navigation.

The SDSP worked with the partner cancer treatment centers during Program Year 1 to expand their existing patient navigation programs. Expanded services included tobacco use assessment and referral, nutrition and physical activity assessment and referral, as well as preventative cancer screening, with a focus on colorectal cancer screening, into routine care for cancer survivors.

**Program Highlight**

A free-standing patient navigation center, housed within one of the SDSP partner cancer treatment centers was established during program year 1. The Navigation Center is staffed by two registered nurses and two social workers. The center provides 24/7 patient navigation services through a call center or walk-in model. Expanded navigation services also include a follow-up call for all cancer survivors who receive a survivorship care plan to address any subsequent needs. The creation of a patient navigation center, along with the expansion of patient navigation services provided, enhances patient services throughout the full cancer care continuum.
The burden of cancer was recently assessed among cancer survivors using data from the Behavioral Risk Factor Surveillance System (BRFSS). BRFSS data is available annually, and has historically been used to plan and prioritize initiatives and interventions. South Dakota was fortunate to have included a subset of the BRFSS Cancer Survivorship Module questions into the 2015 survey. Data from the 2015 survey is currently under analysis, with a report of the survivorship burden data planned for public dissemination in Program Year 2. The 2016 BRFSS survey included the full Cancer Survivorship Module. Data from the 2016 BRFSS survey will serve as the baseline of survivorship burden data for the SDSP.

The SDSP addresses the development of survivorship care plans (SCPs) that utilize both clinical data and cancer registry data. At the launch of the SDSP, there was no clear mechanism within the partner cancer treatment centers to accurately track SCP eligibility and provision. Within Program Year 1, the SDSP worked with the partner cancer treatment centers to develop processes to identify survivors eligible to receive a SCP. The partnering cancer treatment centers now utilize their centers’ electronic health record system to identify eligible survivors, and later verify completeness of this list through the local cancer registry data. By the end of the 3-year project period, the objective is to increase the percentage of eligible cancer survivors who receive a SCP from 10% to 75%.

IN PROGRAM YEAR 1, NEARLY 300 SURVIVORSHIP CARE PLANS WERE DISTRIBUTED ACROSS 5 SITES IN SD
Many of the short term outcomes of the SDSP are focused on increasing survivor knowledge of preventative lifestyle behaviors, treatment and follow-up care. The SDSP has worked with the partner cancer treatment centers in two ways to achieve these outcomes. The SDSP first worked with the existing patient navigation programs to adapt and standardize the resources and services, including:

- emphasis on physical activity and nutrition
- discussion of tobacco cessation
- addressing psychosocial, distress, and behavioral issues
- cultural, religious, and spiritual issues for survivors
- connecting survivors with appropriate resources

The SDSP also worked with the partner cancer treatment centers to identify survivors eligible to receive SCPs, and create a plan to complete, distribute, and track the percentage of eligible survivors receiving an individualized SCP. Included in the SCP is a summary of the survivor’s cancer and treatment history, as well as guidance on potential long-term or late effects from cancer treatment, risk factors, recommended future preventative cancer screening, and follow-up care needs.

Provision of the SCP is expected to enhance survivors’ knowledge of their cancer and treatment history, and encourage and prepare these individuals to adopt healthy lifestyle behaviors. A patient survey is planned for Program Year 2, assessing knowledge of treatment and follow-up care, lifestyle behaviors, as well as satisfaction with the SCP.

Of the South Dakota cancer survivor population:

* Nearly 29% report their health status as poor or fair, compared to 12% in those without a cancer diagnosis
* 18% continue to smoke
* 31% report no leisure time physical activity

*Source: 2014 SD BRFSS*
The SDSP created the Navigator Network to foster collaboration among cancer partners and to provide education and training opportunities for cancer professionals statewide.

To enhance healthcare provider knowledge regarding treatment guidelines for cancer survivors, the SD DOH partnered with the American Cancer Society (ACS) and the George Washington (GW) Cancer Institute to offer the National Cancer Survivorship Resource Center’s E-learning Series to staff of the partner cancer treatment centers and members of the Navigator Network. The multi-part series offers continuing education modules where clinicians can learn about late effects of cancer treatment, coordinated care, and the importance of ongoing preventive care needs for cancer survivors.

In May 2016, GW Cancer Institute provided a full day synchronous training on cancer survivorship and patient navigation in South Dakota. Training topics included: providing high quality cancer survivorship care, survivorship care plans, strategies for successful preventative health screening and nutrition/physical activity intervention compliance. The training was attended by approximately 30 healthcare professionals in the Navigator Network, including patient navigators and community health workers.

The SDSP also collaborated with the SD Comprehensive Cancer Control program and the ACS to host an online palliative care in oncology webinar for cancer professionals. The webinar aimed to improve proficiency in palliative care, addressing benefits across the care continuum, assessing the capacity of a palliative care program, improving collaboration within a setting and with community stakeholders, securing/maintaining accreditation, and providing resources to support palliative care efforts.

The SDSP also promotes other local and national training opportunities to patient navigators through the Navigator Network. A local online learning platform that educates healthcare professionals on the SD QuitLine and tobacco cessation was promoted, as was the ACS Commission on Cancer webinar series, NCCN trainings, and other related patient navigation and survivorship webinar opportunities.
In September 2016, the first program white paper was released. The purpose of the white paper was to describe the development and implementation of SCPs at three health systems’ cancer centers in a rural state. Collectively, these centers serve most cancer patients residing in SD, making the partnership across the cancer centers innovative. Each of the three health systems and their affiliated cancer centers is unique in its history, culture, and infrastructure. In addition, each cancer center was at a different point in the development and implementation of SCPs at the time of the interviews for the white paper. This project provides an understanding and a framework of the processes, successes, and challenges involved in the development and implementation of SCPs throughout each stage in the spectrum. Insights from each health system can be used to support adoption of SCPs in similar low-population states and regions.

The importance is not only in the paper Survivorship Care Plan, but in the “high quality conversation” that occurs between the provider and the patient as a result of the Survivorship Care Plan.
Staff involved in the SDSP from the partner cancer treatment centers were invited to participate in an evaluation survey, assessing their satisfaction with collaboration to achieve the goals of the program. The questions contained in the survey were designed to generate feedback about the strengths, weaknesses and the steps needed to enhance program efforts.

A high level of overall program satisfaction was reported by all partners, with an aggregate mean rating of 9 out of 10 (scale of 1 to 10).

Satisfaction with program leadership received high scores as well. Eight leadership components were assessed, and the aggregate mean rating for each component was between very good and excellent.

Staff from partner cancer treatment centers were asked to rate the quality of the collaboration and partnership among all the participating cancer treatment centers. The aggregate mean for all collaboration and partnership components ranged between good and very good.

Availability of resources was also assessed in the program satisfaction survey. Partners were asked to think about the funding, support, and expected timeframes provided by the SDSP and indicate their level of satisfaction. The program resource assessment components scored high, with a mean aggregated level of agreement of very good or higher for each component.

Lastly, staff were asked to describe what they feel has been the greatest accomplishment of the SDSP at their facility in the last year. We proudly share the following comment as an example of the impact the SDSP has made in only the first year of program implementation.

“Through the work with the SDSP, we have been able to identify areas where improvement is needed and have the staff and resources needed to be able to implement change. Our biggest accomplishment is in our new plan to identify ALL patients from our facility, not just those seen in medical oncology.”
SUMMARY:
The first quarter of Program Year 1 was focused on establishing partnerships with cancer treatment centers to carry out the program strategies. Partnerships with six cancer treatment centers were established, with five remaining at the close of year one. The treatment centers serve a broad and diverse geographic area. Maintaining relationships with the partner cancer centers is vital to the work of the SDSP. The program satisfaction survey of cancer center staff demonstrates high satisfaction with the partnership and the collaborative activities in the SDSP.

Infrastructure and system changes within the partner cancer treatment centers were the primary focus for year one activities of the SDSP. This concise focus ensured the provision of high quality survivorship care plan dissemination and patient navigation services, as well as the ability for accurate and timely data reporting. Approximately 300 SCPs were delivered to survivors from the participating cancer treatment centers in Program Year 1, indicating significant process improvement across sites.

In addition to the extensive amount of planning necessary to establish this type of a program, activities in all six program areas were identified. Program years two and three will focus on further implementation of the specified interventions, including continued development of the expanded patient navigation services and SCP provision, measuring the impact of prevention efforts through surveillance surveys and patient feedback, expanding coordination with primary care providers, and offering education to healthcare providers through training programs and dissemination of program findings.
RECOMMENDATIONS:

1) **Enhance the Navigator Network.** The Navigator Network is in place to foster collaboration among cancer partners and to provide education and training opportunities for cancer professionals statewide. Capitalize on this platform to increase sharing of best practices in cancer survivor care across health systems statewide, and potentially outside the SDSP partners. Host a forum specific to survivorship navigation to further understand the needs for this type of service in the state.

2) **Support tobacco referral training in oncology.** Cessation of tobacco use is critical in improving outcomes for cancer survivors. Healthcare providers are key to cessation efforts and the improvement of outcomes for tobacco users. Clinicians, health departments, and cancer control coalitions have important roles in promoting and supporting cessation. Statewide tobacco referral data shows low provider referral numbers from the partnering cancer treatment centers in SD. To enhance provider knowledge and encourage providers to refer cancer patients to the SD QuitLine, support of a tobacco referral training is suggested. The SD QuitLine offers training on a number of topics that can be helpful to health professionals who interact with tobacco users.

3) **Monitor and assess the capacity for SCP completion and delivery.** Establishing the processes for identification of survivors, and the population, completion, and delivery of SCPs across the five partner cancer centers is a significant accomplishment of Program Year 1. Effort needs to shift to program monitoring, assuring the processes are feasible in order to scale delivery to all cancer patients without compromising the quality of the SCP visit. Throughout Program Year 1, establishing the number of survivors eligible for a SCP has been a challenge for cancer center staff, as processes are refined and the population changes. Data from cancer center quarterly reports, as well as distribution numbers of the patient survey in Program Year 2, will provide early indicators of the success of SCP provision and an opportunity to further evaluate and refine processes, if needed.
References


