Provision of Survivorship Care Plans in Hard to Reach Patient Populations

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More Americans are surviving cancer than ever before due to advancements in cancer treatment and research. As of January 1, 2016, there were more than 15.5 million children and adults with a history of cancer living in the United States.\(^1\) That number is estimated to reach approximately 20.3 million by January 1, 2026.\(^1\) Conversely, cancer death rates have declined 26 percent since a peak in 1991.\(^2\) Rates of five-year cancer survival for the most common types of cancer combined have been improving, increasing from 50 percent in 1975 to 66 percent in 2012.\(^3\) With increases in the five-year survival rate, a focus on long-term survivorship care is of critical importance, now more than ever before.

Long-term survivorship care emphasizes quality, consistency, and advocacy for best care practice in four general areas: disease surveillance, recognition of cancer recurrence, ensuring adherence with healthcare maintenance, and education of the possible late- and long-term effects of cancer therapy. In order to help survivors make a successful transition to post-treatment cancer survivorship and enable them to actively communicate and engage with their providers in these four areas, the Institute of Medicine recommended the development and use of survivorship care plans (SCPs).\(^4\)

A 2005 Institute of Medicine report, “From Cancer Patient to Cancer Survivor: Lost in Transition”, recommended that each survivor receive a SCP to improve quality of life. The SCP is an individualized record that summarizes and communicates what transpired during active cancer treatment regarding the patient’s diagnosis and treatment. Additional content includes: potential late- and long-term effects of cancer therapy; signs of cancer recurrence; instructions for the recommended follow-up, physical examinations, cancer surveillance, and diagnostic testing schedules; education and promotion of healthy lifestyle behaviors for prevention of secondary malignancies; and resources and referrals to support services. A SCP is therefore considered a tool that may equip survivors with the knowledge and skills required for management of
potential physical, psychological, and social needs post-treatment.

The Commission on Cancer (CoC) of the American College of Surgeons has played an integral role in setting the stage for SCP delivery. The American College of Surgeons, founded in 1913, is a consortium of professional organizations that utilizes standard setting to improve survival and quality of life for cancer patients. The first set of standards was published in 1930, and later established into an Approvals Program (now Accreditation Program) that evaluates cancer clinic’s performance against the standards. CoC accreditation is granted to facilities that are committed to providing the best in cancer care while demonstrating compliance with CoC Eligibility Requirements and Standards. To maintain accreditation, cancer programs must undergo an on-site review every three years. Currently, CoC Accredited Programs encompass more than 1,500 hospitals, freestanding cancer centers, and cancer program networks in the United States and Puerto Rico.

In 2015, the CoC implemented standard 3.3 to facilitate implementation of SCPs in cancer treatment centers. Standard 3.3 requires cancer survivors be provided with a comprehensive treatment summary and SCP, and further outlines the timelines, guidelines and standards regarding SCP delivery.

Figure 1. Excerpt from the 2016 CoC Standards Manual

Cancer programs are required to develop and implement processes to monitor the formation and dissemination of SCPs for analytic cases with Stage I, II, or III cancers that are treated with curative intent for initial cancer occurrence and who have completed active therapy. The printed or electronic survivorship care plan must contain input from the principal physician and oncology care team who coordinated the oncology treatment for the patient, as well as input from the patient’s other care providers (outside treatment information), if applicable. If two separate facilities are providing treatment, both facilities collaborate to complete and provide the SCP. In all cases, programs, hospitals, and physician offices should work together to provide the information necessary for completion of a SCP that contains all required elements.
To meet standard 3.3, the SCP must be provided within one year of the cancer diagnosis (or 18-months for patients receiving long-term hormonal therapy), and within six months after completion of adjuvant therapy (other than long-term hormonal therapy). Patients with Stage 0, IV, or metastatic cancer are excluded from the SCP provision requirement. Patients who are seen by an accredited program only for pathological diagnosis, and are not treated or provided follow-up care by the program, are not required to receive a SCP from the facility providing only a diagnosis. The standard also outlines that the SCP should be discussed with the patient, not simply provided by mail, electronically, or through a patient portal. Delivery of the SCP must be recorded in the patient medical record.

To maintain accreditation in 2018, programs must provide SCPs to ≥50 percent of eligible patients who have completed treatment. During the implementation period of standard 3.3 (January 1, 2015 – December 31, 2018), the CoC specifies that cancer programs may choose to initially concentrate on their most common cancer sites while demonstrating progress on expanding SCP delivery to eligible patients for all disease sites. For example, many cancer centers began trial delivery of SCPs among their eligible breast cancer survivor population and later expanded the process into gynecological cancers, head and neck cancers and so on until SCP templates existed for all cancers deemed curable. Utilization of a staged implementation process for SCP delivery allowed many cancer treatment centers to incrementally reach the accreditation standard of providing ≥50 percent of eligible patients who have completed treatment with a SCP. Across the country, cancer programs are diligently working to achieve and maintain standard 3.3 by incorporating SCPs as a standard of care. However, for some CoC accredited cancer programs, implementation in hard-to-reach populations remains a struggle.

**Hard to Reach Patient Populations**

Survivors are typically identified for SCP provision through the health systems’ tumor registry, individual patient pathology reports, and through tracking by patient navigators. This determines the analytic case load and the eligible denominator for SCP provision. Tumor registries track all patients with a cancer diagnosis who receive care of any type at the health system.

Complications in identifying cancer survivors for SCP provision can arise when surgery privileges are granted to private providers outside of a
health system. A cancer patient may have surgical oncology care performed by a private provider with surgical privileges at a health system, but receive the remainder of their treatment and follow-up care outside of that health system’s cancer treatment center. As the surgery took place at the health system, these patients are subsequently included in the eligible analytic case load. The patient is then included in the denominator of eligible survivors for SCP receipt within the health system, despite not being a patient of the health system. As such, many of these patients are hard to reach for SCP provision and discussion, as the remainder of their care occurs outside of the cancer treatment center model.

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 SCPs in a hard-to-reach patient population of urological cancer survivors, including surgery-only prostate patients, receiving care outside of a cancer treatment center model.

Methods

This project used an observational qualitative design. Key personnel for SCP provision at each health system were interviewed, using a structured guide.

Participants

Two health systems and one auxiliary specialty center agreed to share their stories of collaboration. A description of the associated facilities and the associated cancer center(s) is as follows:

- Avera Health includes the Avera Cancer Institute (ACI), which provides comprehensive cancer care at six regional cancer centers and 40 outreach sites in SD and surrounding states. Four CoC accredited cancer centers, located in the SD cities of Sioux Falls, Aberdeen, Mitchell, and Yankton, are partners in the South Dakota Survivorship Program. The Sioux Falls location is accredited as a comprehensive community cancer program by the CoC. The other three rural sites are accredited as community cancer programs.
- Sanford Health operates four CoC accredited cancer centers in a three state area. The Sanford Cancer Center (SCC) in Sioux Falls is a partner in the South Dakota Survivorship Program and is accredited by the CoC as an academic comprehensive cancer program. SCC became a National Cancer Institute’s (NCI) National Community Cancer Centers Program partner site in 2007. In 2014, the NCI
Community Oncology Research Program (NCORP) replaced the NCCCP, and SCC remains actively involved. SCC is also certified by the Quality Oncology Practice Initiative (QOPI).

- Urology Specialists Chartered Ambulatory Surgical Center, LLC is accredited by the Accreditation Association for Ambulatory Health Care (AAAHC).

**Interview Questions**

A structured interview guide was developed to gather information describing the models of collaboration between the cancer treatment centers and the auxiliary specialty center. To explore the processes, challenges, and successes of collaboration, this paper assessed the following questions among the interviewed facilities:

1. How does cancer survivorship fit into the mission of your health system?
2. Tell us a little about your survivorship program and how that is currently set up and administered.
3. When did you begin your collaboration with Urology Specialists?
4. Would you describe for us the factors or the context that led you to reach out to this population?
5. What has happened to date?
6. What urological cancer patients are currently provided with survivorship services as part of your health system’s collaboration with Urology Specialists? Is it just prostate so far, or is their SCP provision for bladder and urethral cancers, kidney cancer, penile cancer and testicular cancer as well?
7. How are surgery only prostate patients identified for survivorship care plan provision?
8. According to CoC Standard 3.3, if two separate facilities are providing treatment, both facilities must collaborate to complete and provide the SCP. How does this process work for prostate patients and your partnership with Urology Specialists?
9. How do navigators access patient information to complete the SCP?
10. Tell us about the timing and method(s) of delivery of survivorship care plans for prostate patients (mailed SCP accompanied by phone visit / full survivorship visit).
11. Who has oversight responsibility for the survivorship navigators working with Urology Specialists and how was this decided?
12. What resources are provided by each facility to support this role?
13. Does your organization bill for any of the urology survivorship services? If so, how is this time or visit billed? Do other funding mechanisms support this service / navigator?

14. Tell us about the benefits and risks associated with utilizing a shared navigator role.

15. Are post-treatment services (medical follow-up care, psychosocial services, educational opportunities / resources) provided by either facility for these patients? If yes, please describe these services? How is that decided?

16. What lessons have been learned throughout this partnership?

17. How can this process facilitate other health systems?

18. What hard-to-reach populations remain that are currently not receiving SCPs?

19. Is there a similar approach that could be utilized to reach those populations?

20. What else do you think would be important for us to know about the partnership between your health system and Urology Specialists?

Models of Collaboration to Reach Survivors of Urological Cancers

Survivors of urological cancer, including bladder, urethral, kidney, penile, prostate, and testicular cancer, approach 6.5 million in number. Prostate cancer survivors alone represent one in five of all cancer survivors in the United States. The majority (91 percent) of prostate cancers are discovered at a local or regional stage, for which the five-year relative survival rate approaches 100 percent and the ten-year survival rate for all stages combined is 98 percent. Prostate cancer has one of the most encompassing inventories of adverse long-term and late effects of the disease and its treatment, including urinary incontinence, sexual dysfunction, bowel dysfunction, fatigue, pain, and adverse psychosocial and relationship effects. Additionally, the long-term health-related effects of treatment for patients with localized prostate cancer are found to continue more than ten years after treatment. Beyond provision of high-quality surgery or radiation, it is imperative for clinicians to provide high-quality survivorship care to prostate cancer survivors. In the following narrative, we’ll take a look at how local health systems collaborated with a center specializing in urology (here forth referred to as the specialty center) to improve their quality of care and patient experience.

The specialty center’s mission is to provide comprehensive, compassionate, and patient-centered care. Administration realized that
cancer survivorship plays an integral part in being able to carry out that mission, especially for patients facing an arduous list of adverse effects from treatment. The practice felt strongly that it would be beneficial for the patient and their primary care provider to receive a summary of their cancer treatment, potential long-term and late effects from the cancer and its treatment, and recommendations for future follow-up and testing.

Since the private providers at the specialty center maintain surgery privileges at local health systems, their patients may receive surgery-only treatment, such as radical prostatectomy, at their preference of health system. Often, these patients receive the remainder of their care at the specialty center. The following models of collaboration present successful methods for accessing a hard-to-reach patient population for provision of SCPs.

**Model #1**

The first health system and specialty center collaboration for survivorship began in 2013. The survivorship collaboration was built off of an existing working agreement between the two partners based on surgical privileges for specialty center private providers, which in turn helps the health system build relationships for referrals with patients requiring more advanced treatment. The specialty center has ten private providers with surgical privileges at the health system. Each month, roughly 30-60 patients are connected from the specialty center to the health system for surgery alone, or, for some (approximately 10-15 percent), a combination of surgery and more advanced cancer treatment (e.g., radiation or chemotherapy). For surgery-only patients, follow-up care is provided by the specialty center. However, because the surgery took place at the health system, the patient is thus included in the denominator population for SCP provision to meet accreditation standard 3.3. Seeing a gap in SCP provision to this unique population, a strategic decision was made by the health system to offer dedicated resources to provide care to this patient population that might not receive any direct or additional services from the health system other than serving as the location where the patient’s private provider performed the surgical removal of their cancer.

The two facilities determined the best way to serve this shared patient population would be through hiring a genitourinary (GU) oncology nurse navigator to provide patient navigation services, SCP creation and delivery,
and recommendations for follow-up care. Although designed around survivorship care, the GU navigator’s role is more than just delivery of the SCP. The GU navigator position is employed and supported financially through the health system to provide the full continuum of cancer services in accordance with their mission. As a navigator, this individual is available to provide information to help the patient understand their treatment options, follow-up with the provider(s), outline future screening needs, and address ongoing care questions. In the course of treatment, the navigator is given the opportunity to visit with the patient face-to-face at the specialty center. The navigator participates in “option talks”, a conversation with the care team and the patient to discuss all of the surgical and treatment options to decide which treatment is best for the patient. The patient is also given written information about all of the different options. Early on in the position, this was a way for the GU navigator to get information about the treatment decision process from both the patient and provider perspective. Now, however, unless it is a complex case, the navigator doesn’t typically participate in this initial visit. Currently, the GU navigator meets with approximately 75 percent of patients during their post-operative stay in the hospital (which typically lasts 36 hours). If the navigator is not able to meet with the patient during their post-operative stay, or if the diagnosis is not clear during this period, then a survivorship visit will take place at the patient’s six-week follow-up appointment or by phone after the SCP has been mailed to the patient’s residence. In-person delivery is the preferred method, according to received patient feedback. A copy of the patient’s SCP is then stored within all three facility EHR systems.

Throughout the collaboration, the navigator has found success by having a physical presence at the specialty center. Availability on-site has allowed the navigator to build relationships with staff that have developed trust in the role. The navigator stated the importance of being present, helping out even if it isn’t a task within the role, answering questions, and being sensitive in relation to who is providing care in each context. A self-directed nature is required for success of this role.
The GU navigator has access to three individual EHR systems, including the health system’s EHR, the EHR utilized by the health system’s cancer treatment centers, and the specialty center’s EHR. The GU navigator, however, must be onsite at the specialty center to access the EHR due to technology security protocols dictated by the health system. Thorough review of all EHR documentation is required in the development of a single SCP, requiring 15-60 minutes per patient. The specialty center provides the navigator with access to the same records the physician has, and the documentation from the patient’s chart is used to define and support the care plan.

Management of the GU navigator position is unique, as the individual technically works for both facilities that each have their own set of expectations. For this reason, a healthy working relationship between facilities is required. Although the navigator is an employee of the health system and the supervisor is located at the health system, the navigator spends the majority of time at the specialty center in order to have access to all three EHRs. The collaboration requires flexibility to allow the employee to travel between physical locations as needed.

The shared GU navigator position provides benefits to both facilities. Although the financial responsibilities fall onto the health system, the benefit of accessibility to the GU patients who may otherwise be hard to reach is of tremendous value, as provision of SCPs to this population helps the health system reach the CoC accreditation requirement of SCP provision to ≥50 percent of eligible patients who have completed treatment. Additionally, the health system credits the GU navigator for building trust with the private providers at the specialty center and allowing them to feel more comfortable referring their patients back to the health system if more advanced treatment is required. Since these are private provider patients, the health system chosen for surgery is based on both the patient and private providers’ choice. The presence of a GU navigator from the health system, and development of positive relationships can help persuade patients and providers to choose the health system for their surgery. This benefit alone outweighs the cost of providing the resources to fund the GU navigator role - the money is
invested up front in hopes of a long-term gain. Most importantly, the service fits with the mission of the health system in providing the best care to patients and, as stated by health system staff, “is just the right thing to do”. Overall, the health system sees the value in strengthening their standard of practice by offering navigation services, SCP delivery, and follow-up care recommendations to all patients associated with the health system, even if that association is by surgery alone.

For the specialty center, the benefits of providing working space and EHR access to the GU navigator are many. The specialty center is able to support their mission of providing comprehensive, compassionate, and patient-centered care through this collaboration, as well as enhance the patient experience. Outside of EHR access and provision of and working accommodations to include computer, printer, paper, postage and other office supplies for the shared GU navigator role, the service is essentially free of cost for the specialty center, and becomes an asset with the potential to market these services to prospective patients. This is currently a free service to the patient as neither facility bills for the GU navigator’s time.

Management at the health system identified that the nature of the person in the navigator role is key, regardless of how the partnership is set up. A large part of the success is having the right person in the position. It is a tough role managing expectations of two unique facilities in addition to patient expectations, and it requires someone with a leadership background to be successful in such a self-directed position.

Opportunities exist to expand the comprehensiveness of the services offered through this collaboration and possibly expand this same model to other hard-to-reach patient populations. Patients at the health system have access to a wealth of resources, including a social worker and chaplain to meet some of their psychosocial needs. The shared patients in this collaboration with the specialty center do not yet have access to this. The same model could be used in other population gaps, such as dermatology patients, head and neck cancers, and breast cancer patients receiving surgery only from an outside provider, with the understanding
that it takes time and patience to build a successful collaborative relationship.

**Model #2**

The second model of collaboration for survivorship care was initiated in May 2017 between the specialty center and another health system. The mission of the collaborating health system is dedicated to the work of health and healing. Survivorship fits into the mission as it is really the transition of healing to the next step of general health and well-being, with a focus on diet, exercise, and holistic well-being. Discussions began in February 2015 on the topics of survivorship care and collaboration for clinical research trials between the facilities. In March 2015, the health system hosted an inservice on survivorship efforts for staff of the specialty center. Then, in March 2017, management from both facilities met to discuss how to integrate survivorship to benefit both parties. Through the health system’s involvement in the South Dakota Survivorship Program, funding was provided to support a GU oncology nurse navigator to work with surgery-only patients of the specialty center. A GU navigator was hired in May 2017 and the position began working with the specialty center in June 2017.

The GU navigator provides patient navigation services, SCP creation and delivery, and recommendations for follow-up care to patients of the specialty center receiving surgery-only treatment at the health system. Patients are identified for SCP eligibility through the tumor registry at the health system, review of weekly pathology reports, and also through the health system navigators. Additionally, schedulers at both the health system and the specialty center typically notify the GU navigator of any GU patients scheduled for surgery-only cancer treatment at the health system.

Two individual EHR systems are available to the GU navigator, including the health system’s EHR (which is the same EHR used by the health system’s cancer treatment centers) and the specialty center’s EHR. Travel to the specialty center is not required for the development of the SCP as the navigator has access to both EHRs on-site at the health system. Documentation is pulled from each facilities’ EHR to support the SCP development. The care plan then outlines late and long-term side effects
from treatment, life after treatment, follow-up care needs and educational materials including advance care planning, nutrition, physical activity, and psychosocial support. The navigator’s contact information is also provided in case the patient has further questions. Utilization of two unique EHRs can be time consuming, with development of an SCP requiring 30-45 minutes for completion. For this reason, access to the specialty center’s EHR within the walls of the health system is necessary for successful time management. Once an SCP is completed, it is loaded into the health system EHR and a copy is shared with the specialty center to be loaded into their EHR.

As the GU navigator initially started in the role, visits were scheduled in-person with the patient to review the SCP and the navigator would make frequent trips to the specialty center. The navigator has since decided that this was not a valuable use of time, nor was in-person delivery a preferred method based on patient feedback. The navigator now spends most of the position based at the health system, determining that mailing out the SCP and following up with a phone-based visit seems to be the preference of most patients. The phone-based visit is resource saving, as it typically takes about 15 minutes to review the SCP with the patient. The navigator has also noticed that patients tend to be more open to discussing sensitive subjects over the phone rather than in person. “Cancer looks different for GU patients”, according to the navigator. “Many of the patients don’t even see themselves as cancer patients, and therefore, their expectations are different.” GU patients often undergo surgery and are essentially cured with no further treatment required. These patients are typically treated more like surgical patients than cancer patients. The SCP and follow-up care instructions are also much less detailed than for other types of cancer. The unique setting and patient population makes these survivors more difficult to reach. “Not all patients want the conversation” associated with the SCP. According to the navigation team, it seems that the less intensive treatment for the majority of this population makes them less interested in the SCP. However, overall patient feedback on the GU navigation services and SCP provision has been positive.
Management of the GU navigator position is again unique, as the individual technically works for both facilities. Oversight for the position comes mainly from the health system, but the navigator also works closely with the Nurse Director at the specialty center. The navigator has been cautious to be collaborative, without making extra work for the staff of the specialty center. The collaboration again requires flexibility to allow the employee to travel between physical locations as needed to provide services, although for this partnership, most services are provided by phone.

The GU navigator position is currently funded through provisions from the South Dakota Survivorship Program. However, the health system plans to sustain the position beyond the grant funding period, seeing the benefit of the role. The specialty center supports the navigator position by providing access to their EHR management system and working accommodations to include computer, printer, paper, postage and other office supplies while on site. There is currently no fee to the patient associated with the provided survivorship services.

For the specialty center, the benefits of providing working space and EHR access to the GU navigator are the same as previously mentioned: supporting their mission and enhancing the patient experience. The benefit to the health system is improving the percentage of eligible patients that receive a SCP for the CoC accreditation standard. The real benefit, however, is for the patient who is now able to receive a SCP and a team approach to care.

In order to make the collaboration work, buy-in is required from each facility. Private providers need to be supportive of the navigation services, and the GU navigator needs to provide high quality services with minimal disruption to the private providers and patients. A dedicated site-specific navigator is also needed for success. SCP creation is time consuming and needs to be individualized for each cancer population. With the uniqueness of each population, it takes some time to figure out how to enhance the SCP’s impact for the patient.
At this health system, opportunities exist and are being explored to expand navigation services and SCP provision to patients of dermatology, thyroid, and other surgery-only patient populations. Surgical-only patients are difficult to identify and reach, whether inside or outside of the health system. Patients typically fall into three groups for cancer treatment: 1) those receiving care through the standard medical oncology unit, who are easy to reach as standard survivorship processes are established, 2) surgery-only patients internal to the health system, who are slightly more difficult to reach, but processes are being established, and 3) external surgery-only patients from specialty private providers, who are very difficult to identify, which is why survivorship collaborations with specialty providers are a necessity. Every surgery-only cancer type has unique challenges, but with patience in process development and site-specific training, SCP provision will continue to expand.

Long-term survivorship care is of critical importance as the population with a history of cancer, as well as the five-year survival rate, continues to increase. Survivorship collaborations with specialty providers can enhance care collaborations, as well as enhance the overall patient experience. The two health system collaborations outlined above offer unique models of partnership for survivorship care provision with a specialty provider to access a hard-to-reach population of surgery-only patients. Each health system developed a model of collaboration that fit with the unique needs and resources of their health system.

For one health system, the GU navigator’s on-site presence at the specialty center was highly valued. The health system credits the navigator’s physical presence at the specialty center for the development of trust and a mutually beneficial collaboration between the facilities. The navigator expressed the importance of being present and available to jump in and help out where needed, while remaining sensitive to who is providing care in each context. According to this health systems’ received patient feedback, in-person delivery and discussion of the SCP is preferred.

In the second model of collaboration, maximizing efficiency within the role was highly valued, leading the GU navigator to work mainly from the
health system. The navigator has been cautious to be collaborative, without making extra work for the staff of the specialty center. The navigator communicates frequently with the Nurse Director and the schedulers at the specialty center to identify patients scheduled for surgery-only urological cancer treatment at the health system. In this health system’s experience, patients prefer to receive their SCP by mail, followed by a phone conversation regarding the document. The navigator expressed that patients tend to be more open to discussing sensitive subjects over the phone rather than in person.

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. In both models of collaboration, a self-directed nature is required for success in the GU navigator role. Both collaborations also require flexibility in management, allowing the employee to travel between physical locations as needed to provide services. Due to the uniqueness of the shared role, a healthy working relationship and strong communication between facilities is a necessity. Both facilities must agree that survivorship care is best for the patient.

The benefits of collaboration on survivorship care efforts are vast. For the specialty center, the main benefit of the partnerships is the increased capacity to support their mission of providing comprehensive, compassionate, and patient-centered care. The specialty center could also market the services to prospective patients, supporting an enhanced patient experience. No drawback was identified for the specialty center. A tremendous benefit of collaboration for the health systems is accessibility to the GU patients for provision of SCPs. This helps the health systems reach the CoC accreditation requirement of SCP provision to ≥50 percent of eligible patients who have completed treatment. Additionally, the collaboration helps encourage referrals back to the health systems when patients have advanced treatment needs, which helps balance the cost of supporting the navigator role. Most importantly, the collaborations help support care coordination among facilities and provide a team approach to patient care.
References