

Treatment Summaries and Survivorship Care Plans—Who is Responsible for Ensuring They are Used?

Lillie D Shockney, RN, BS, MAS

Though there are expectations of oncology providers to create a detailed treatment summary of the cancer patient's treatment as well as document a survivorship care plan to be followed, going forward, there isn't a clear sense of who is to do what and how all of this is to happen. A piece of paper is, well, a piece of paper. Without a structured, consistent method of creating these documents, disseminating them to the correct providers, and conducting follow up to ensure they are followed, they have no true value.

There also remains disagreement among oncologists and PCPs out in the community who is the medical professional really qualified to be following up and monitoring cancer survivors long term. Add to this that no published studies have been conducted yet demonstrating that these documents benefit patients, has resulted in confusion and delay in the development and implementation of such survivorship programs. Regulators however have incorporated into their standards that such documents are to be in place and demonstrated when surveys are conducted by the American College of Surgeons who accredit cancer centers and cancer programs.

Historically, when a patient received a diagnosis of cancer, the patient's PCP referred their patient to an oncology specialists with the expectation that the patient remain permanently under the oncologist's care. Due to the shortage of oncology specialists (projected to be between 41-48% deficit by the year 2020), and the steadily growing population of cancer survivors, we know that retaining a cancer survivor long term by an oncologist is no longer realistic or practical. A study conducted at the Lombardi Cancer Center with PCPs being surveyed showed some interesting results that impact the ability to transition patients from the oncology team back to their PCP. These results were:

<60% of PCPs agreed that they possessed the skills necessary to care for treatment effects in cancer survivors (focusing in this survey on breast and colorectal cancer patients.)

<50% of PCPs felt very confident in their knowledge of testing for recurrence or caring for the psychosocial effects of cancer.

23% of PCPs reported feeling very confident in their ability to care for the late physical effects of cancer or its treatments.

Only 38% of oncologists agreed that PCPs have the skills necessary to initiate the appropriate screening or diagnostic work ups to detect recurrence breast cancer

25% of oncologists strongly or somewhat strongly agreed that PCPs possess the skills necessary to provide follow up care related to the effects of breast cancer or its treatment.

Many institutions are working to develop a shared care model for survivorship care. Survey questions associated with this model reflected the following results:

38% of PCPs preferred it compared to 25% of PCPs who felt the oncologist should be the primary responsible doctor for follow up survivorship care; 10% of PCPs preferred a PCP led model.

On the flip side, 57% of oncologists preferred an oncologist led model; 16% preferred a shared care model and 2% preferred a PCP led model.

When asked questions regarding the management of late effects from cancer treatment, 23% of PCPs and 77% of oncologists felt very confident in their knowledge of how to manage these patients.

85% of oncologists stated they were very confident about ordering appropriate tests for detecting recurrence of disease where as only 40% of PCPs had the same confidence level.

Perhaps the most telling survey results are the following:

Many oncologists expressed less confidence in PCPs than the PCPs themselves. 75% of PCPs believed that they have the skills necessary to initiate appropriate screening or diagnostic workups for detecting recurrence of breast cancer where as only 38% of oncologists thought the PCP would know what to order and how to evaluate for such a medical problem. And when it came to psychosocial issues, oncologists felt they were the most qualified to address these issues for patients (51%) compared to the skill set of a PCP (8%)

Why is this type of survey data important? Because if the providers of care for cancer survivors lack faith in one another it will be incredibly difficult for them to successfully implement a survivorship program together—under any model, shared care or otherwise. This means that the treatment summary and survivorship care plan is not going to be a living document used for determining who is to do what, when, how and for how long but instead merely pieces of paper that get filed into the medical records of cancer survivors.

What can you do as a navigator? Conduct a different type of barrier assessment- this time being on the Perhaps a lot of the problems providers are facing on both sides of the equation (oncologists and PCPs) is fear of the unknown. The oncologist doesn't want to relinquish control of his/her cancer patients. At the same time the PCP doesn't feel comfortable assuming oncology care responsibilities that previously were never on their plate. Steps to be taken then include the following:

1. Start with a specific type of cancer population—commonly breast cancer due to it being a large volume diagnostically with a high survival rate overall.
2. Hold a meeting with the oncology faculty for that patient population and discuss :
 - a. Their understanding of the need for a treatment summary and survivorship care plan for their patients

- b. Their comfort level in transitioning their patients back to the patients' PCPs in the community, and the timing of this transition (commonly based on stage of disease, treatment received and prognostic factors)
- c. Create an educational program for PCPs in your community so that they have an opportunity to learn from your oncology team how to care for patients with a history of specific type of cancer. This should include the importance of not over utilizing healthcare resources by doing routine staging work ups which are no longer standard of care.
- d. Create a team that includes yourself, a few willing oncologists and interested PCPs in creating a treatment summary and survivorship care plan documents that address the needs of the care team and the patient. (for example, PCPs want to know what they are responsible to do. Giving them a lot of details about the number of rads a patient received to the left breast may not be useful; telling them to monitor the patient for potential brittle rib bones in the radiation field and possible heart issues as delayed side effects is what is important for the PCP to know.)
- e. Document who is responsible for what—who will order the patient's mammograms? Address side effects from hormonal therapy? Make sure she gets her annual flu vaccine? Without a crystal clear picture, there is risk of assumptions being made and no one doing what needs to be done on behalf of the patient.
- f. Determine as a team what the expectations will be of their mutually shared patients too.
- g. Determine how this new program will be assessed for its successfulness. (this will likely involve your expertise in following up to ensure patients kept their appointments, get their appropriate screening, and follow recommendations made regarding their ongoing survivorship care.)
- h. Pilot with 10 or less patients a transitional shared care model and follow up with feedback from all faculty involved. Buy in is key to the success of this program
- i. Also obtain feedback from the patient what she felt helpful, what was not, and from her perspective what she still needs to feel confident and have assurance that her care is coordinated.

Once you have a survivorship care program that is functioning well within one specific patient population, you are then ready to take on another patient population that is high volume with a large number of survivors. Without this type of planning and coordination, you run a risk of these documents being merely added paper to a medical record with no benefit achieved for your patients.

Still having difficulty getting everyone to work together and communicate? As time progresses, oncologists will simply not be able to have their clinics primarily filled with long term follow up. They will be inundated with the need to see more newly diagnosed. This type of pressure will force the issue and they will need to relinquish control of their cancer survivors from their direct oversight and rely more on

other providers to monitor them long term. The goal? That their cancer survivors will never “need” the oncologist’s skills again.