Critical Elements in Designing a Cancer Survivorship Program

My name is Paula Lewis-Patterson. I’m the Executive Director of the Office of Cancer Survivorship at the University of Texas MD Anderson Cancer Center. This presentation today will focus on Critical Elements in Designing a Cancer Survivorship Program.

I will start with the objectives as you see on the screen. So, the first one is really to discuss the changing trends in cancer survivorship and why those are so important; identify elements and components of survivorship care, which we’ll talk about what is survivorship care and how you define survivorship care; and describe survivorship programming related to planning, implementation, metrics and evaluation. And this will absolutely help us discuss how this can be done. And then, I’ll discuss the diverse models of survivorship care, how survivorship care can be structured.

So, “who is a cancer survivor?” From the definition from the National Cancer Institute, and this was in 1996, a cancer survivor is an individual who’s been diagnosed with cancer and from the time of diagnosis, they’re considered a survivor through the balance of his or her life. The families, friends, and caregivers are also essential --- in this --- in this definition because the cancer journey also affects them. And therefore, they are included in the definition.

When we look at estimated numbers of cancer survivors, as of January 1, 2016, there are approximately 15.5 million cancer survivors in the U.S. And this number is expected to increase to 20.3 million survivors by 2026. So, looking at the trends, you know, what really --- is --- is driving cancer survivorship? There are --- a couple of things – or a number of things that --- that are driving cancer survivor and the increase in those numbers. One is improving cancer treatment. Cancer prevention is very important. And also, we know that our population is aging. With that, we know cancer rates increase with age. We also know by 2020, two-thirds of our cancer survivors will be 65 years or older. And with that comes comorbidities and as people --- have grown older -- - have gotten older, we know that the chances of hypertension, diabetes, and all those other things that we see as people age will probably be those issues that we will be addressing with our cancer survivors.

One of the --- thing --- things that is really important is how --- people are prepared --- how patients are prepared for their journey. So, actually, in 1974, --- a physician by --- Fitzhugh Mullan was diagnosed with cancer. He viewed cancer in three different and distinct phases. The first phase --- was considered --- as he considered was acute. And this is time of diagnosis, also the time when treatment plans are being developed for the patient. And, the goal in this phase is to get the patient to remission. The second phase is intermediate. During this time, you will hear oncologists say this is watchful waiting or watchful monitoring. --- We actually look at those things that or --- this is the time period where there might be a long increase or --- this is the time when there is highest degree for the primary cancer to occur. And, at this point, I’ll talk more
as we go along into this presentation about the importance of a treatment summary. The next phase, where we consider cancer survivorship belongs, is long term. This is after the patient has been cleared or has completed treatment. And then the patient also has has been visited or has visited their oncologist. So, therefore, the surveillance period is over, and once that occurs, we look at long term survivorship. What are those things that would cause an impact on the patient as they have finished with cancer treatment. This is the post cancer treatment phase. And during this phase, we are actually focused on wellness because early on, we’re focused on disease and diagnosis, and chemotherapy, and all those things that go along with the cancer treatment. So, we’re trying to change that paradigm once they get into long term or kind of those chronic issues that occur after cancer treatment, and we are looking at a model of wellness.

So, where to start? And that’s always an interesting question. “How do you start? Where to start?” We get that question many times. And first, identify a champion. You need someone to support you. Think about, you know, what is really going on in either your practice or your institution, especially regarding leadership, leadership objectives, and leadership roles, and priorities. The next, you should interview selected providers. You might want to look at physicians or advanced practice providers in your own practice or in your academic setting. Or at who refers patients to you, who do you refer patients to – whether that’s community or or in your practice setting. And, those are the people that you really want to start a conversation with. If you are in a private sector and you’re interested in a cancer survivorship program, survey the community providers. And those community providers could be nutritionists, social workers, people that provide OT or PT services in the community. And that absolutely starts that ball rolling because you will need those referral services if you are not in a large population, those referral services, to send patients out regarding treatments or modalities that they might need. And, earlier doctors. It’s really great to get people that are enthusiastic and are supportive of these efforts. Once you get that, then you start looking at how those conversations should should continue and how can we get some impetus behind it. And, the determinant what is the mission of your program, absolutely. What do you want to achieve and how do you plan on achieving that? So, those are the first things that might be that that we have found very helpful when starting a cancer survivorship program.

Essential to that would also be data collection. So in your practice or clinic service, “who are your survivors?” You might have breast survivors or you might have patients with prostate cancer. So who are those survivors? And then, “what are their needs?” - In 19 --- I’m sorry --- In 2015, the American Cancer Society published an article and it was “Current Unmet Needs of Cancer Survivors.” And they did an analysis and reported information regarding what their findings were. What cancer survivor patients were saying that they were lacking. And, one of the major responses or findings was patients were concerned about body image. They were also concerned about pain and symptoms. So if you hear this from these patients, these are probably those things that you should identify up front. The second --- the second thing --- that ---
that in the findings was financial. As we know, cancer is a very expensive diagnosis and disease, and so patients wanted to talk about affordability of services or how services were not that affordable. That is also a need and that might fall under some of the psychosocial, social work concerns for patients. And then, education. Most patients were interested in what to expect. --- What --- What do I expect now that my cancer treatment has been completed? Then, you want to look, again, at what’s available in your community. Again, --- you might --- occupational therapy, physical therapy, psychologist, nutritionist. And collect that data and get some baseline data regarding those issues.

Additional data is “what’s missing?” --- You would --- I would encourage you to do a SWOT analysis to figure out what’s missing. You need to set some type of population endpoints. “When is a patient eligible for survivorship?” It might be you look at age ranges or dates of diagnosis or categories of malignancies, from the time of treatment to the last --- to the last treatment, to the last time the patient came to see you. So, one example is, you might set eligibility deciding that people that are 18 years or older --- who are diagnosed with a --- with a cancer diagnosis. They’ve been seen in your clinic. They have finished with treatment. They have no evidence of disease. That might be the population that you would start with. So --- so think about your endpoints and then identify your sources of data. Your sources of data could be tumor registry data if you have that; appointment data; and it --- or it can be something like billing codes. But, you need to start with a base of --- who --- what patients would be eligible --- or what patients would you want to center this survivorship program around. It could be several patients. You might want to one diagnosis. Or you might want to do a survivorship program where there are several different diagnoses of cancers and then center that program around those particular needs.

Key stakeholders are essential. So as you see in this diagram, --- it --- it really does take a village. --- You --- as the oncologist, you need to define what that care plan is and --- you --- you’ve made that decision on the care plan, and --- you --- you’ve followed this patient from treatment through surveillance and now through long term survivorship. There would be some staffing needs and so, think about stakeholders that are business operational and --- how --- how would you cover those issues. Advanced practice providers are very important, your physician assistants and your advanced nurse practitioners. --- This --- This group is really essential in providing care for patients. All of your allied health colleagues would be very important. Integrative medicine or any types of support services that you might need. Nursing personnel in your clinic, how are those things addressed as far as follow-up phone calls, scheduling the patient. And, your referring physician. ---- Your community physician would be the one that would --- or the patient’s community physician would be the one that helps co-manage this patient. And remember, please don’t forget the patient is really in the center. And the patients really need to have an idea of what will happen. Remember, one of their needs was “what to expect”. So all of this revolves around the patient but all of these --- case --- key stakeholders are extremely important in the process.
One of the things that you will need to do is identify tools. And, you can contact established survivorship programs. We have one here at MD Anderson. There are many across the county. And find tools that might help you. Our guidelines are published online. Our guidelines and our algorithms for survivorship are available online. But, also, there are other entities that can help you, and online, Journey Forward is a really good resource. American Cancer Society has a great resource. So as far as Journey Forward, if you would go online and pull that up, there are options to help build a survivorship care plan. There is a mobile App. There are also survivorship library sponsored by the George Washington Cancer Center and CDC and American Cancer Society. There is a National Cancer Survivorship Resource Center toolkit for providers and it actually gives you great information regarding how to build a program. And then, CancerWise is also – and these are just a few. There are many online. These are just a few that you might want to use. So try not to reinvent the wheel, if you can. There’s great information, reputable information, online and available, if that’s what you’d like.

One of the things we also provide in Survivorship Clinics – we look at and these are the Domains of Care from the Institute of Medicine. So, the first domain is surveillance. And this is really looking for late effects and late malignancies that might reoccur or any new diagnosis or new cancers. Patients could have recurrence of first of the primary cancers with second, third, and fourth cancers. We have seen that in our practice. Prevention and screening: All of the prevention and screening guidelines are usually based on regular lifestyle changes to prevent cancer and risk assessment. And these are smoking cessation. These are exercise and diet and those types of things regarding changing lifestyles. Late effects: Late effects are patient-specific. So it might be chemotherapy treatments that would cause long term effects. For example, some chemotherapies, as you know, affect cardiac. There are things chemotherapy treatments that affect the lungs. And so when we look at a late effect management, we’re looking at just health maintenance and observation of vital organ function. Psychosocial: And I think when we look at everything remember, this is a total patient so it’s not just one entity. We want to look at this entire patient regarding, you know, where they are as far as anxiety. You might need to do a referral. Body image is a huge concern of many, many patients. There is also the issue that I’ve discussed before regarding financial issues. There are a number of articles written regarding financial toxicity regarding cancer care. And so these things will concern many concerns need to be addressed and reviewed during the Survivorship Clinic visits.

So, what we have here at Anderson, and as I had alluded to before, we have built clinical algorithms. These are evidence-based, peer-reviewed algorithms. And the algorithms actually for each disease site – if you look on the left, actually defining what when the patient is eligible for survivorship. They’re all different. We have 47 survivorship algorithms. So with this one, this is cervical cancer. You can see vulvar cancer treated with radiotherapy, three years post treatment, and no evidence of disease. The other, when you look down, it’s cervical and vaginal cancer,
five years post treatment and no evidence of disease. Again, we look at our models of care. We also review surveillance specific to those patients, risk reduction and early detection, monitoring for late effects, and psychosocial functioning. And any point in this algorithm, it will give you decision decision spots where you can make some determination of what needs to do next what you need to do next.

--- We also have online and available and this one is the gynecologic cancer survivorship bone health, because we know with many treatments, there are side effects regarding bone health. This is just one of many supportive algorithms that help the providers regarding decision tools and decision steps to address those issues regarding bone risk factors, regarding bone health.

So, again, the survivorship guidelines and algorithms, you can pull up the National Cancer Institute Office of Cancer Survivorship. And it offers guidelines for health care providers and professionals from various sources including MD Anderson. There are many out there. And this website is cancercontrol.cancer.gov and you can see it at the bottom /ocs/resources/healthcare. And those are really, really great starts where you do not again have to have to reinvent everything from scratch.

In 2005, the Institute of Medicine published this landmark book. The name of the book was From Cancer Patient to Cancer Survivor: Lost in Translation. What the Institute found was there was lack of communication between the patient’s oncologist and primary care providers. What patients were saying, it was great when they were in treatment because they had almost the whole army surrounding them while they were in treatment. They had the doctors, the nurses, they knew what would happen next. And they knew about their biopsies, they knew about their visits. When treatment was completed, they felt alone and abandoned. And then they were out there to fend for themselves. So, many of them had a great deal of trepidation about how do I go forward. This landmark publication really has spurred the conversation regarding patients’ oncologists communicating with primary care providers regarding coordination of care. As a matter of fact, there is also the Commission on Cancer and their 2015 guidelines and standards. Actually, they started in 2012 but 2015, made a recommendation to develop a process that the institutions need to have a process to provide patients with a document which was a comprehensive treatment summary and follow-up care plan. This meant when that patient was probably when they’re finished with treatment and seeing the oncologist, and they were in that surveillance, so that intermediate phase, patients needed to be given a document of all of the chemotherapy treatment, and all of their if they had radiation or surgery and what to expect in that follow up. That helps the patient, because remember patients are not necessarily transitioned to a Survivorship Clinic until they are three, four, five years with no evidence of disease. Therefore, when those patients are in the community and they’re seeing a community physician, the community physician really needs to have information regarding what the cancer treatment what cancer treatment the patients had. And this this is also a tool that the patient can give their community
doctor as far as followup. --- And so that whole miss --- that whole issue of missing communication is very, very important --- when we --- when we think about this whole continuum as patients are surviving cancer. And their cancer care and they are survivors, and then how do they carry on, how do they go forward, how do they journey forward --- and --- and --- and manage their life as well as manage their health.

What we’ve done here at the University of Texas MD Anderson Cancer Center, --- we have --- we have an electronic medical record and we’ve actually looked at the Commission of Cancer standard. It’s standard 3.3. And this is what we are working toward giving patients at the end of their treatment. So it’s very specific. It has information regarding who the oncologist, who the surgeon was, or radiation oncologist. If the patient only saw a surgeon, there’s a way to delete those other columns. There’s the cancer diagnosis and stage, and all of these are really standards and requirements from the Commission on Cancer based on ASCO requirements for this particular treatment summary.

The treatment summary also gives background health information. There is information about surgery, the type of chemotherapy and radiation.

At the very end of the treatment summary, we have put recommendations for follow-up care, and many of those recommendations for follow-up care would be the patient. Remember, --- they are --- they have finished with their treatment, they are in surveillance. But these patients now need to see the oncologist. Depending on the disease, sometimes it’s six months for every two years, and on and on. And, those are also embedded in our treatment summaries. We’ve also managed to work with our electronic medical record and we have – we call it a Passport Flowsheet for recommendations for care. This document is used when the patient visits the Survivorship Clinic and these are recommendations for surveillance and prevention. What we were able to do, based on the algorithm and based on preventive services, were able to recommend, for example, --- in --- on this slide, that the patient needed to have a bone density, we placed a date. We also have the functionality to identify if the patient would have treatment here on our campus or treatment in the community. We’ve talked about the future date and future location if the patient wants to be treated here or elsewhere, and we are able to do that for any of the recommendations. If there is not a recommendation that is specific to the patient – because you see on the screen, for women, there’s the breast exam, mammogram; and there’s prostate screening. So, if those aren’t --- aren’t relevant as far as the recommendation, there’s nothing that’s filled out. We’ve worked for this record to be available. Patients actually come to the Survivorship Clinic annually and usually, it’s every year for three years, sometimes more. We see patients every year for three years or sometimes every year for four years. And we’re able to use that same document and make that recommendation and follow up with the patient regarding --- if they --- if they had their mammogram or if they had the bone density. And those types of issues that we have recommended for care.
The other part of documentation for our survivorship program again would be late effects. This is another document that we’ve developed and it can be documented if the particular late effect was active or it’s been resolved. And what the recommendations are. So, that’s just one of the things that we have developed with our electronic medical record.

Again, in getting back to how to design a survivorship program, you need to pilot a model. So, you can select a model of care, and I will give you some more information about that in just a few minutes. But this is the how-to. You select a model of care that is appropriate for your service. You’ve developed a financial plan, and you just need to pilot it, if that is what you choose to do. But you really should pilot it. It’s a small test to see how it would work. Define your patient population. Define your care delivery model. And evaluate any metrics, and I’ll talk about metrics in just a moment. You during this pilot, hopefully you’ve identified your early adaptors and your collaborators. So it’s communication, communication, communication with those people and with your colleagues that will really help take care of your patient. And you want to test this pilot. What you might like to do is, on a small scale, if you’ve identified a certain population, you might want to look at those patients that have completed their treatment. They are out whatever many years for no evidence of disease. And you might want to start on a --- on a day or half a day, bringing one or two patients in, and and --- and working out or mapping out the whole process of how to deliver survivorship care. So, I have a couple of models.

One of the models is oncology-based model. And this is here at the University of Texas, we do have several programs that are specific for breast or colorectal. We have a stem cell transplant. So that’s the treatment-based programs. And then, we have comprehensive stand-alone programs and especially in our Pediatric Center. They see all diseases and all types of pediatric cancer survivors in that one. Or you can do a shared model. This is a shared care between the oncologist and primary care provider, usually in a community, where the oncologist or the Oncology Service sees the patient for their cancer care but all of the other care is followed up by the community or primary care doctor. And then there’s a community-based program which includes referrals to the provider. The patient comes in to see the oncologist or the Oncology Service, the advanced practice nurse regarding surveillance and and follow up, but all referrals are done to the community, which could be a nutritionist, a PCP, or a physical therapist. So, whatever model fits best is the one – and you can test it – fits best is the one that would work for you. You just have to make that decision.

Once you select a model, then all of the things that we know, you need to analyze it, and analyze as far as operations regarding patient volume; time; space utilization, which is always an issue – where are these patients --- where are these patients meeting? Are they meeting in the same place that they had their treatment? Or they’re meeting some place else, in another clinic, in an integrative medicine clinic, or are they meeting in a cancer prevention clinic? That’s really for your practice to make that decision. And then, the categories of service: What types of things do you do now? Now, when you
look at the models of care regarding surveillance, prevention, psychosocial, and late effects, that’s not just exclusively for survivorship programs because that can be done any time during this patient’s cancer journey. What we particularly look at in the Survivorship Clinics is that model of wellness. Patients are not in treatment. Therefore, we’re really emphasizing --- that --- that cycle of wellness and health. You also would look in --- for your return on investment. “What are your returns on investment?” “Is that freeing up an oncologist to see more patients as far as newly diagnosed or follow up patients?” And then, do you have either advanced practice provider that would also in tandem with that clinic, as that clinic --- is operatio --- is operating, the advanced practice provider would see --- the --- those cancer surv --- those cancer survivors. This will help if the advanced practice provider identifies an issue and needs a quick consultation or needs to consult with the oncologist. They’re --- they are right there. If not, then those decisions on how that needs to occur really should be discussed.

Formulate a business plan: The biggest question that we get is --- how or --- who will staff the clinic? As I have alluded to before, here at the University of Texas MD Anderson Cancer Center, our Survivorship Clinics are staffed by advanced practice providers, and there are providers that some of them -- many of them -- also help patients during the treating phase and then a half a day or a day, they devote their time regarding visiting with the survivorship patients. So, that clinical location. We do have certain centers where the volume is so large that there is no clinic space and we’ve worked that out by finding a different clinic space for that patient. Identify your infrastructure and what kind of resources will be required. So, it’s really a mapping out process, a --- a SWOT analysis, lots of discussion. And then finance and revenue and expenses. How does that work? How should it work? What is your return on investment? Those are the things that many of the leaders in your --- in your practice, especially in an institution, would want to know.

So, once you pilot the process, define how patients will be transitioned to the clinics, and communication, communication, communication. Talk to your stakeholders, keep them engaged, evaluate. The pilot is really important because in a pilot, you don’t have to have a large volume of patients. You can do that with three or four patients and see how that works with your practice. Again, you’ve determine those endpoints, when a patient is eligible, how many patients would be eligible for transition, and then, discuss, implement, and evaluate those practice changes to make sure patients are really receiving what they need to receive, and that the practice or your clinic is able to do the operational issues that they are now engaged in, whether it’s --- treatment --- taking care of patients in treatment and taking care of patients in a Survivorship Clinic program.

So, three critical success factors: Commitment from leadership: We have been very fortunate here that our leadership is from the top. We have dedicated resources and sometimes, finding those dedicated resources have not been that easy but we’ve worked on that. Again, we have advanced practice providers in each one of our clinics.
We have 12 Survivorship Clinics. And we’ve garnered a great deal of buy-in from our stakeholders. It’s not always easy, but what we’ve learned is, as a program, as a clinic has been successful and we’re able to talk about that program and show data of how many patients have returned to the clinic, how many patients have received treatment summary, how many patients have followed up on the recommendations, we’re able to get buy-in. It can be very slow, but once once you’ve got your foot in the door, it is very, very helpful to show some successes. So, start with successes. Start with those earlier adopters and people that really are willing to help and really support your Survivorship Clinic.

So just as a recap, I think this helps when you’re looking at the various phases. Leadership is critical. Champions of the program, critical. Identify your mission and goals of your program. Data, especially valid data, SWOT analysis. Identify that patient population. Identify your endpoints. Look at your resources, and if there are any gaps in practice, which you might not have, but if a patient needs a certain service, how does that patient receive a service. For example, if a patient needs services from the social worker or physical therapist or the psychologist, how does that patient receive that, whether it’s in your practice or whether it’s referral? Your core practice tools. Again, algorithms are available. Ours are online. Try not to reinvent the wheel. Network with other survivorship programs, and have conversations on how those things are done. Select a model. I discussed the model the various models, whether they’re service-based models, whether there’s an integrative model, whether there’s a community-based model, and develop a financial plan appropriate for that model. Again, you do not have to start large. You may start small and see how that builds and then go forward. You design and implement your program, map out your process, stay close to your stakeholders, and talk about what your measures of success are. And evaluate your metrics. Our metrics have more to do with the number of patients that are transitioned to a Survivorship Clinic, the number of patients that actually keep their appointments, the number of patients that receive treatment summaries. We look at if the service that has developed the algorithms, if they are concordant. Are they following what that algorithms that they have created, are they following the algorithms, and if they are, that’s great. If they’re not, then you go back and ask, do the algorithms need to be updated. And then, one of the things we’ve started looking at is patient adherence. A provider will recommend that a patient have a mammogram. We’ve recommended it this year. When the patient comes back next year, did the patient have the mammogram? So, it’s not only concordance; it’s patient adherence. And then improve and deploy the program. Expand your stakeholders, expand your program as appropriate, and really talk about how that should work. I sincerely hope this has been helpful and great success with your survivorship programs.