

CANCER SURVIVORS

SYMPOSIA SERIES

Issues & Solutions for Life After Cancer

New Approaches to Survivor Health Care

May 14, 2007

Survivorship Care Planning

Craig C. Earle, MD, MS

Dr. Earle is an Associate Professor of Medicine at Harvard Medical School. He is also the Medical Director of the Lance Armstrong Foundation Adult Survivorship clinic at Dana-Farber Cancer Institute. He is a nationally-recognized researcher in measuring the quality of life for cancer patients and survivors, and is a pioneer in the development of survivor care plans as a standard of care for cancer survivors.

There are going to be a lot of recurrent themes here. I'm going to be talking a bit about survivorship care planning. As Dr. Hart said, I had the privilege of being involved in this report. The Institute of Medicine is a group that gets together to comment on health care policy, areas where we can be doing better, where increased funding should be, etc. The survivorship report was titled *From Cancer Patient to Cancer Survivor: Lost in Transition*. It's talking about the transition, the point when people are finishing their primary treatment for cancer and moving on to become a survivor. This was really a new take on this in many ways because up until then people had sort of thought of cancer as this crisis that happens to you, and then you have your treatment and, hopefully, you're cured, and that's it. Mission accomplished. But as someone else who used that phrase recently learned, that's not always the end. "It's not over when it's over" applies to many things.

So, the very first recommendation out of this report was to recognize cancer survivorship as a distinct phase of cancer care. You've seen in a couple of the graphics that Dr. Hart showed, that cancer survivorship is, thinking about it as this thing, this state that in many ways cuts across many different types of cancers. So, as opposed to just thinking of a patient who has had breast cancer and now has finished their treatment, and then they are moving onto other things, there are actually things that that patient has in common with someone who had colon cancer or had lymphoma. This entity, in and of itself, that has common issues. Some of these issues cut across, no matter what the primary cancer was.

First of all, everyone is concerned about surveillance for relapse. We'll talk about that a bit later, but that's often the first thing that comes to mind when we start talking and thinking about survivorship care. As Dr. Hart alluded to, the last of these sessions was about late

and persistent effects of treatment, either effects that happened and came on during the treatment, whether from surgery or something like that and then persists, perhaps lifelong, or sometimes there are things that show up many years later and are related to the treatment, such as organ dysfunction. There can be heart effects from some of the chemotherapy drugs that are used, or kidney effects. Mobility – if you've had certain types of surgery. Fatigue is a very common thing that cancer survivors report. And as Dr. Hart mentioned, lymphedema. A lot of the treatments effect people's hormonal balance, either because they're taking hormone drugs themselves or drugs to block hormones, or they've had surgery or radiation that will effect hormones that then effect sexuality, fertility, bone health and various things like that.

And then there is the issue of second cancers, which can come up for several reasons. One, whatever caused that first cancer may cause another cancer, either in the same organ or somewhere else, because a lot of cancers have the same underlying effects whether it's a genetic predisposition to some types of cancers or whether it's environmental exposures (tobacco smoking, things like that).

There are also definitely crosscutting issues around employment or insurance. We know that cancer survivors have more difficulty getting disability insurance and life insurance. What about health insurance if you work for a small employer or are self-employed? Or, because of fatigue or some of these other things, have actually lost your job? Getting health insurance. These are crosscutting issues that a lot of cancer survivors face.

The next session in this series is on psychosocial issues. Fear, fear of recurrence, fear of morbidity, effects on relationships, cosmesis, cosmetic effects sometimes of cancer treatments. Cognitive – we're increasingly recognizing chemo brain, difficulties concentrating. These things sometimes are leftover from a successful treatment of cancer.

But, then in bold, I also want to step back and say that we recognize that a lot of studies have shown that many have little or no long-term effects, that cancer survivors are not all these debilitated people necessarily, and some even have positive effects. I remember one of my own patients telling me that if they are reading a book and it doesn't grab them within four or five pages, they throw it away because they have this new perspective on life and they are not going to waste time with things that aren't causing enjoyment.

So, the first recommendation is to consider cancer survivorship its own entity and think about it in that way. The second recommendation is that patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan – the 'survivorship care plan.' I remember talking to my wife about this at one point when we were working on it and she just could not believe that we don't do this already. But we don't. In general, at no point does someone sit down and go through and say, "here's the type of cancer you had, here are all the treatments you had, here's what everything is going to be going forward", and coordinate it and lay it all out in a very concrete way. But I know in my own practice I find often as patients approach the end of their treatment...I am a medical oncologist so I'll be giving chemotherapy for six months or so and it's around five or five-and-half months when patients often start getting anxious about what happens now. Up until then they're coming every week or every other week, they're

seeing everyone, they're being checked, they're having blood work, but then after that we're just going to let them go for several months. Having a plan, knowing what is going to happen going forward, is something that can be very reassuring.

Why do we need a survivorship care plan? It is to communicate both the survivor – this is something to empower patients – as well as other health care providers (their primary care doctor, the different types of oncologists that may have been involved in their care) what has been done and what needs to be done in the future so everyone is on the same page about that. I think another important point is also promoting a healthy lifestyle to prevent recurrence and reduce the risk of developing other medical problems and other cancers. We'll talk a bit about that as well.

Why is this so important in cancer? Why are there communication problems in cancer in particular? Cancer often involves multidisciplinary care. So you may have a cardiologist for a heart problem, maybe there's a heart surgeon, but it's uncommon to get much beyond that. However, on average, most cancer patients have actually more than three cancer doctors somehow involved. They may start off with a primary care physician who first recognizes the symptom. Maybe they went to a gastroenterologist to have their rectal cancer diagnosed. Then they were seen by a medical oncologist and a radiation oncologist for treatment, and then eventually they end up with a surgeon. There are five doctors who are involved. The care that's involved is often very complex. It's treatment that takes place in a variety of settings across time and space. What I mean by that is that at Dana Farber in Boston we try to have multidisciplinary clinics where all the doctors, different surgeons, radiation, are all there together and can all come up with a plan and do all the treatment together, but it just doesn't always work out that way. Sometimes maybe part of the treatment has already taken place. For radiation, for a patient who lives farther away, it can be very inconvenient to come every single day for six weeks for treatment. So you end up just naturally, no matter how much you try, with patients getting treatment in a variety of different places by different doctors, and with different types of medical records. Some are on electronic records, some are on paper records, and some are hand-scribbled notes. How do you put all that together and figure out what is going on and what has taken place? Often a lot of this takes place in isolation from the primary care doctors. We often think of primary care doctors as the coordinator, the central person who then deals with all the different specialists. But in cancer, I think more than in a lot of other conditions, once oncologists get a hold of you, you have this very intense relationship with an oncologist, or multiple oncologists, for a number of months and often the primary care physician may be getting letters, but maybe they're not.

The idea of the treatment summary and care plan. First, the treatment summary. It's very simple stuff. It's the diagnostic tests that were performed, and what sort of scans were done to establish the stage, for example. What type of cancer was it? Where did it start? How advanced was it? What was the stage? What was the grade? Are there tumor markers, which are often blood work things that we follow? And what were the dates? When did all of this happen? What was the sequence of radiation and surgery? When was everything completed? What exactly was the treatment, surgery, radiation, chemotherapy? Was the patient on a clinical trial? Do we know of toxicities that already occurred during treatment that may persist or cause problems down the road? Were there

other issues that came up? Were there difficulties coping? Were there insurance issues that came up? And then, I think very important, what is the contact information of the people who treated the patient? Can we bring all of this information into one place? It's surprising. Someone had their radiation out somewhere. They may never really need to see that doctor again, unless something happens where you need to know if a particular part of the body was radiated or not. It would be very helpful to have something that summarizes that and has contact information of who exactly that was and how to get hold of them. Identifying who is going to be the key coordinator, or coordinators. Identifying who is going to do things going forward for this patient.

There are different reasons that we follow patients after cancer. There are some people who argue and have some research behind the idea that in many cases patients may be just as well off if we say call us if you have a problem. But there are different things that we do to try to improve the quality of life for our patients. The thing that always comes to mind is surveillance for recurrence – finding if the cancer comes back, to find that early. I'll say a bit more about that in a couple of minutes. As I mentioned, a lot of the surveillance we do is actually looking for new cancers. I treat colorectal cancer as a major part of my practice, and when we do colonoscopies it's not actually to look for recurrence of that cancer, because that would be very uncommon, it's more for new polyps, things that could turn into new cancers. And then there are late effects of treatment. Lifestyle and behavioral interventions. And then something else I'll talk about, the non-cancer care. Not just focusing on the cancer that you had and whether it has recurred, but what about screening for other cancers, other medical conditions, not letting other things fall through the cracks. Then, lastly, to be able to educate our patients about resources. There are resources available to help if there are legal or insurance types of issues, job retraining, whatever. There are groups out there who have made it their mission to try to help people who have a history of cancer.

So, for the first part, should we do lots of tests to see if a cancer has come back? This is a very controversial area that comes up all the time. It's the thing that people tend to think of first when we talk about caring for survivors. The problem is that in most of these cases there isn't a lot of evidence that doing a lot of tests helps. There are some specific situations, some diseases, but by and large most of our cancers, once you've had your primary treatment, that's really the most important thing. After that, in a way, the die is a little bit cast, not completely, but it is. Studies that have been done looking at whether we should be doing scans every three months – bone scans and brain scans, and all sorts of things like this – at the end of the day people don't seem to live any longer by doing all of those things. In fact, they can be stressful. They can adversely affect quality of life, let alone insurance and economic types of effects. In any of these situations, if we're wondering if we should be doing a lot of tests, we need to think about whether the tests that we're thinking about actually detect recurrences earlier than it would otherwise become apparent. If so, does early intervention actually improve the outcome of the disease, or are you just telling people they have a terminal cancer a couple of months before it would actually come up? Just last week, one of our patients said to me, "So, we'll be doing scans as a preventive thing, right?" I said scans don't prevent anything. That's not really what this is about. That's why I think a lot of the focus of survivorship care

should actually be about the other aspects of health and of life and trying to prevent new cancers and living better in many ways.

Another thing people say about doing lots of tests is that there is psychological reassurance to having these tests done and having them normal, that it gives psychological reassurance. But there definitely are risks of intensive testing. As I mentioned, in several of the large randomized studies that have been done of intensive screening, for example in breast cancer, they found that there is no benefit in the terms of quality of life and in fact it may be more stressful. A lot of my patients tell me they don't sleep for two days before a scan and then they don't sleep the day after waiting for the results. And part of this is that our tests are not black and white, yes/no, and clear/not clear. There is a cyst in the liver. What do you do? Do you do biopsies? Do you take people to surgery? Would you be able to do anything about it if it turns out that it's a recurrence? There are often abnormalities on almost any scan that's done.

These are some data from a study we did a few years ago where we were looking at breast cancer survivors and saying if they've survived their breast cancers, truly survived them, and you follow them out long enough, what do breast cancer survivors die from? First of all, most patients diagnosed with cancer today will not die from it. Seventy percent of patients are cured. They go on, if you follow them, to die of other things. What you can see is that it is things like heart disease, lung cancer, diabetes, colon cancer – many of these things are lifestyle related. Some of them may actually be impacted by the late effects of treatment. If you've had radiation to the heart area, that can accelerate heart disease, but heart disease is also a common thing. Diabetes – so weight control is important, and exercise is important. Not smoking. You saw lung cancer, you saw chronic lung disease, those are smoking-related illnesses. Colon cancer – there is good screening for colon cancer. If people are screened we can greatly decrease the incidence of this. So someone who has been cured of breast cancer still has all of these other things that we need to focus on and not lose the opportunity. It's a shame to cure someone of one cancer and then have them die of something else that we could have prevented. So both the cancer and the non-cancer health care are very important. Some people have said that getting cancer may be a "teachable moment." What they mean by that is that often, when there is a big health care crisis, people are more motivated to change their behaviors. I find, in particular, getting a diagnosis of cancer is often when people stop smoking. That's when they quit smoking. Whether it's lung cancer or not, even if it's something that was probably unrelated to the smoking, that's a good time to get people to do that. People will become very interested in nutrition and wanting to change their diet, or exercise. We want to make sure we help people do that and to take this opportunity.

In terms of the non-cancer care, there is some evidence that some cancer survivors may lose touch with their primary care physicians and other specialists. This can happen for a variety of reasons. When you get a cancer diagnosis, you spend the next six months or year undergoing very intensive treatment with all these specialists. You probably don't have time to follow-up with your primary care physician. Patients with asthma may not be seeing their pulmonologists, etc. There is often loss of touch that, when the dust settles on the cancer, all of this needs to be picked up a little bit. There is also some suggestion maybe that there is a lack of clarity around the roles of what different physicians should be

doing for cancer patients. If there is a lack of clarity, there is the possibility that non-cancer care could fall through the cracks in some way. That's why the survivorship care plan should explicitly identify who's going to follow patients for recurrence of their cancer and who is going to screen for other cancers. In some of the research I've done this has been an area where there is the most confusion. Patients, maybe who have had colon cancer, expect the oncologist to order their mammograms and pap smears and these various things. The oncologist may see that as the primary care physician's point of view, that they're just following them for the cancer that they had. This is where there is some of the greatest disconnect about who is going to do what. Who is going to provide routine health maintenance – flu shots, screening for lipids? One of the main ways that I got involved in all of this actually, got interested in it, was realizing that some of my patients were assuming that when I was following them for colon cancer I was also checking their thyroid or screening their cholesterol levels – and I was not. I was assuming that their primary care doctor was. I realized that some of these things could be problems.

The goal is to optimize communication and coordination of care. There certainly is an important role for primary care physicians in this. There is no one model that fits all. Some oncologists may want to do everything. Some primary care physicians can do everything. It doesn't have to be a certain type of doctor or combination of doctors, or even specialized clinics necessarily that can do this sort of thing. So there is an important role for primary care physicians. Part of the reason for that is that this doesn't just apply to oncologists, I'm sure, but there is a workforce issue coming up. This is from a paper that was just published this year, 2007, showing the projections of the oncologist supply in between these ranges – the low and the high bars here – over the next several years. But if you look at the number of cancer patients, there is a variety of things, we have an aging population, cancer is a disease that people as they get older becomes more common, we're going to have more cancer patients, more cancer survivors. There is more that we can do for people now. If you go back 10 or 20 years it was surgery and that's it – maybe a little bit of radiation. Now there are all these new treatments. There are things we need oncologists to do. So the demand is growing very much, outpacing the supply of oncologists. This study was undertaken and really comes to the conclusion that we need to start now training more oncologists, more people in the workforce who will be able to care for cancer patients. And this is actually largely just looking at cancer patients. Add in, now, an increased recognition of survivorship issues, and you have other manpower implications of that as well.

To conclude, the idea behind the survivorship care plan, I think, is that in most cases more important than the specifics of what the plan is, is that everyone who's involved, the patient being empowered as much as they want to be or as they can be, and all of the doctors that are involved, be clear on what is going to be done in the future, for screening the cancer, for non-cancer care, and for routine health maintenance, etc., and who is going to do it. Whose responsibility is it? Work out amongst the doctors who is going to do what. That will go a long way toward ensuring quality cancer care. Thank you, very much.