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Making Cancer History\*

### Alma Rodriguez, MD tells a story of Leadership Challenges

Alma Rodriguez is a professor in the Department of Lymphoma/Myeloma. Since 2005 she has served as Vice President of Medical Affairs. In an interview conducted in 2015, she talks about responding to a 2005 Institute of Medicine Report on the needs of cancer survivors by creating a survivorship clinics.



# Building Survivorship Services

Shortly after that, the Institute of Medicine report was published....in 2005, and it's called, From Cancer Patient to Cancer Survivor: Lost in Transition, and ...really the main message of that report ...is that patients felt they were lost as they transitioned from having been under the care of an oncologist and being treated for their cancer ... because the health community did not want to take them on as patients. Sometimes the primary care providers were afraid of assuming responsibility for the care of these individuals, because they felt, you know, once you've had cancer, God only knows what will happen after that....Or the patients, worst yet, had lost their insurance.... Many lost their jobs...

Our President, Dr. Mendelsohn at the time, felt that it was important that we integrate cancer survivorship as into our care delivery system.... I was asked to take it on when the implementation phase was deemed to be the right time....We formed a steering committee, first of all, multi-disciplinary.... [W]e held focus groups, we got input from providers, we got input from patients and their families. In the end, what we heard both the providers and the patients tell us was, the patients were accepting of the idea that maybe their focus—the focus of their care was no longer going to be necessarily the cancer itself.... They wanted to feel that their oncologist, or the community of oncologists who were expert in their disease, were still linked to that survivor care.

We didn't say, 'immediately upon completing chemotherapy you must transition them to survivor,' that's not what we said. We said, 'at what point do you, the clinicians, consider it safe to transition to survivorship'? The doctors' opinions were, cancer care doesn't end until the patient has reached a point at which the risk of relapse is fairly minimal to nil. That's when it's safe for me to say, "You're a survivor". ... [W]e delegated that responsibility and accountability for determining the time point of appropriateness of transition to the primary providers. And we said it has to be risk-based. So to do that, they built what we call algorithms of transition. So for disease X, when would be the appropriate time point to transition? For disease Y, what would be the appropriate time point for transition? And then we built the actual care model. So in other words, you're not just going to toss your patients out there. You have to tell us what are the key care domains, or elements without four domains—we built the domains based, again, on the Institute of Medicine report.

First of all, you have to do some aspect of surveillance for second cancers. You also have to do prevention in early screening. You have to monitor for late effects of the chemotherapy or radiation or surgery, because unfortunately, those will happen and some patients may be at higher risk than others. So we call that a late effects monitoring. And then lastly, psychosocial health. Did these individuals get back to work? Are they OK mentally? Are they chronically depressed? Chronically anxious? What is going on in their lives? So those four domains of surveillance, late effects management, cancer preventions and psychosocial health, those four key areas had to be addressed in every single algorithm. But it was up to the disease sides to tell us what do we put in those boxes..... [E]ach disease category has its own potential late risks, potential consequences from the treatment and from the disease itself. ... So there's all of these disease-specific knowledge that we built into these models of care. So the providers feel comfortable, I'm not just sending these patients to a clinic where somebody's going to say, "Eat vegetables." That's not it. They're going to have, you know, a delivery of care that is aligned with these concerns that need to be addressed downstream. We built the survivor care clinics in the same way that we built the acute care clinics; in other words, the Breast Center had their own breast survivor clinics, the Gynecological Oncology Center has their own gynecologic survivors clinic. Head and Neck has their own head and neck survivor's clinic, etc....

The other challenge was the operations. Where do we find the space? Where do we find the rooms? Who is assigned—who is going to be assigned now to do survivor clinic?.... [I]t became clear that really, one of the benefits of the survivor care model is that you can deescalate the intensity of the visit to being more health-oriented. And again, remember what I said about Physicians are not always the most well-trained in health and motivation training. Sometimes the mid-level providers and nutritionists and social workers—so we built partnerships of this other tier of providers, who could then help the patients maneuver through these others issues....

So we started off, of course, doing pilots in a couple of clinics, first of all to test the model to see if it was feasible.... We designed it to fit, like I said, the psychology and the structure .... and the operations of our own organization. And being that we have multi-disciplinary disease-specific clinics, and that the patients felt most comfortable in that closeness to their primary clinic, we built the survivor clinics for each disease group for patients with certain categories of disease within that same group. So in gynecology, for example, we built a gynecology survivor clinic in the Gynecology Center. How we would start off is simply by looking at their patient populations and saying, you have X-number of patients who come to your clinic on a yearly basis. We notice that X-number of these patients have not had any treatment for the last three to five years. Would you not consider these patients to be well?

[W]e were asking people to, for lack of a better word, divorce themselves from their oncologist.... I mean, there is a bond that forms between the Physician and the patient, and particularly in a situation where the patient perceives that their lives have been saved by this individual. And so it is very emotional, it can be very emotional. It can be difficult, both for the patient and the Physician. We found that in some cases, it wasn't necessarily so difficult for the patients, again, as long as they knew it was within the same clinical environment where they were cared for before, but in fact, it was more traumatic for the Physicians because they felt that seeing these patients who are well from the perspective of the cancer, who had survived the cancer and were still free of the cancer, that that was the height of their day, that was the most enjoyable part of their day, and we were going to deprive them of that. So that was a challenge, the psychological separation.

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# **About This Content**

This interview clip was taken from an in-depth interview conducted for the Making Cancer History Voices Oral History Project. This ongoing project currently contains almost 500 interview hours with MD Anderson institution builders.

The transcript has been edited from the original.

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