

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Removing Mystery from Myeloma: Management of the Elderly Myeloma Patient'

Description:

Join Alicia and Lizette as they speak with Dr. Marc Braunstein, a Board-certified hematologist, medical oncologist at NYU Winthrop in New York, NY. This is episode four of our five- part episode series, '*Removing Mystery from Myeloma*'. On this episode, Dr. Braunstein explains how management of myeloma differs between younger and older patients. He stresses how treatment is not solely based on age and shares the other factors that are taken into consideration when determining how a patient may respond to treatment. Dr. Braunstein discusses minimal residual disease (MRD), the role of autologous and allogeneic transplant for myeloma patients and the difference between palliative and hospice care.

Transcript:

Alicia: Welcome to *The Bloodline with LLS*. I am Alicia.

Lizette: And I'm Lizette. Thank you so much for joining us on this episode.

Alicia: Today, we will be speaking with Dr. Marc Braunstein, a Board-certified hematologist, medical oncologist with a focus on the care of adults with hematologic malignancies, particularly multiple myeloma. Dr. Braunstein completed his Fellowship at NYU Langone Medical Center and then joined the Division of Oncology/Hematology at NYU Winthrop in July 2017 working to enhance the autologous stem cell transplant program and further developed the innovative clinical trials program that provides their patients with unique and novel therapies. Thank you so much for joining us, Dr. Braunstein.

Dr. Braunstein: Alright, well, thank you for having me.

Alicia: Well, Dr. Braunstein, thank you so much for joining us again on this episode. For those listening, we encourage you to listen to our other episode with Dr. Braunstein where we spoke about how to choose a myeloma doctor, what questions to ask about diagnosis and follow-up and improving bone health as well.

On this episode, we are going to jump in to speaking about one of the topics being the management of the elderly myeloma patient, but Doctor, before we get into that, we actually spoke with, a young adult, on this podcast and he was diagnosed in his twenties; and we had went to a conference with another guy who was diagnosed when he was in his late teens and we are finding that, although this is a disease of older age, we are seeing that a lot of younger people are being diagnosed. Is there a reason for that? Are there studies that are showing more of an indication as to why that could be?

Dr. Braunstein: Yeah, Alicia, that's a great question. You know, those are extremes for patients to be diagnosed in their twenties, because the median age is still in the late sixties, but certainly the incidence of plasma cell disorders such as MGUS or myeloma, they're increasing and part of that may have to do with the increased awareness of this condition. For example, internists often know to order the initial blood test to work-up a patient who may have, incidentally, found to have anemia. And that can lead to a referral to an oncologist to begin to work patients up for myeloma. It may also have to do with certain exposures. In the last episode, we talk—we spoke about 911 first responders. There are also patients who may have been exposed to certain organic chemicals or pesticides that may increase the risk. And I think, also, with the aging population, I think we are just detecting sort of the precursor phases to myeloma more and more. For example, it's estimated at about 5% that people over 70 have MGUS and a large percentage of that population may not even know it. It may go undetected until they develop a little anemia or a little kidney

dysfunction. So, I think part of it has to do with just the increased appreciation for the disease and more testing.

Lizette: Yeah; we have been getting more and more people that have been diagnosed so early and we keep saying that that's not something that's so common, but people are coming to us because they want to connect with other young adults or other younger folks that have been diagnosed since the majority of the folks are older.

Dr. Braunstein: Sure; and younger individuals, may have the benefit of being, you know, more fit and being able to tolerate many of the treatment regimens for multiple myeloma. And, you know, more and more therapies are coming out every year and so, even though this can be sort of a devastating diagnosis especially for someone who has the rest of their life ahead of them, being so young in their twenties, they should be encouraged that there are many effective treatments for this disease and that patients can live for many years with this with good quality of life.

Alicia: Absolutely. And for those listening who would like to connect with another person, we have a resource called the LLS Community, which is an online platform where people can create a profile, log in and speak with other people who may be in a similar situation or have a different diagnosis, but are able to provide, you know, important information to help with the survivor's journey. And you can find out more about that resource at www.lls.org/community.

Alicia: So, Doctor, you spoke about, myeloma within younger patients and why that may be the case. And we know that management of the elderly myeloma patient can be challenging which, you know, because of increased burden of comorbidities and, I'm assuming, reduced resilience to treatment and other things, so how is the management of myeloma different for an older patient?

Dr. Braunstein: Sure, regardless of the age of the patient, we really have to tailor our treatment for multiple myeloma for each specific individual. And when it comes to elderly patients, which we may say are about 65 or maybe 70, or maybe we are talking about frail patients that are just in poor physical shape regardless of their absolute age. When it comes to these patients, they have specific issues that we have to integrate into our treatment planning. For example, ahh, they may have other comorbidities, other medical conditions that could impact their disease or their treatment; for example, they may have had diabetes, or they may have had kidney dysfunction that long predates their diagnosis of myeloma. also, normal aging is associated with a progressive decline in all physiologic systems, so we really have to approach them with sort of a geriatric expertise to consider the normal aging process and also their specific complications related to other medical conditions or aging. and we really have to tailor our therapy to each specific patient. Now, that doesn't mean it's solely based on age. We really take all these factors into consideration. There are even scoring systems to try to predict whether patients are more frail and may respond less well to more aggressive therapies. So, we really have to tailor our therapy to the individual patient and their overall condition.

Alicia: Absolutely. You presented at one of our blood cancer conferences And, for those listening, I encourage you to visit www.lls.org/bcc to see if there's a conference taking place in your area. And, at that conference, you spoke about myeloma; and you had a slide that showed a Rubik's cube and you, basically, spoke about how there are so many great therapies and how it's kind of just figuring out how to use each one and personalize each one for a specific patient. So, when it comes to stem cell transplants and the evolving role of that, would you be able to tell us more about the role of stem cell transplant in myeloma?

Dr. Braunstein: Sure; sure; and thank you for the positive feedback. I really enjoyed that conference and I also echo your sentiment. I thought it was great, just

myself, to hear some of the inspiring talks and I encourage patients to attend the local one as well. Treating cancer, specifically multiple myeloma is not like an assembly line where everyone gets the exact same pieces of treatment. Every individual myeloma is unique, and each patient comes with their own story and their own condition and we have to take a lot into account. Every patient doesn't just get the same boiler plate treatment, ahh, as the other patients. So, the ways we do that is first, by looking at the individual biology of their myeloma, looking at their--the genetics of their myeloma and trying to tailor the treatment based on that; then taking into account their other medical conditions and their overall, what we call, their performance status or fitness; and also, talking with them about what their needs are. What their goals of care are and what their perceptions about how the treatment is going to play out and, you know, for example, if they are still working 10 hours a day as an investment banker, or are they just interested in making sure that they can continue to, you know, jog every day, or spend time with their family without too much fatigue. So, there are a lot of nuance decisions that go into the, ahh, process of deciding which therapy is best tailored to which patient. and historically, the main decision, when initially approaching a myeloma patient, was whether that person was a candidate for an autologous stem cell transplant and that was, in the past, solely based on their age being greater than or less than 65, but that has changed significantly and we no longer look at age as a hard cut-off for an autologous stem cell transplant which is sort of a consolidative measure after the initial, myeloma treatment. And so, autologous stem cell transplant still plays a critical role, and we can talk more about that, but age is not really the determining factor alone to see if a patient is a candidate for this procedure.

Lizette: It's really how fit the person is, right? Physically fit, the person is, not just the chronological age?

Dr. Braunstein: Right. So, you could have a 75-year-old marathon runner in New York, or you could have a 60-year-old debilitated person in a nursing home; and so,

age is not really the only cut-off. We have to take into account, you know, for example, do they shop for their own groceries? Do they prepare their own meals? Do they have any baseline dementia? Do they have other medical conditions that would just put them at too high a risk of complications from a particular therapy? So, there are studies that have been done to try to quantify this into a number to be able to more objectively stratify patients into frail, or less frail, and those have been associated, actually, with survival depending on how frail they are. But, nevertheless, we do take all of these factors into account and then tailor the therapy based on their overall fitness.

Alicia: And that's so great for our listeners to hear because I know it can be very confusing because I mean even the conferences that I've attended, I hear a certain doctor that have a certain number, a certain age that they won't budge on; and then you hear doctors that are saying, you know, we really can't go by age, and it is dependent on how that person is, and how well they are, so I think that's very important for listeners to hear so they know that the option is there, and it depends on other factors other than it just simply being their age.

Dr. Braunstein: Absolutely; and even more so patients who may think they are too old for treatment or family members who might say, you know, "my Mom or my Dad are 90. What right do they have to be treated with all these, you know, anti-myeloma drugs." And I say quite the contrary. You know, we can tailor regimens that are well-tolerated even in the older populations and that can, potentially, give them more quality years of life without too much detriment of treatment side effects. So, one should never really approach the treatment of myeloma solely from a numerical point of view of their age.

Lizette: And talking about transplants also, I know most myeloma patients tend to get auto transplants, autologous. Is there a role for allogeneic transplants for myeloma patients?

Dr. Braunstein: Yeah; that's a great question Lizette, and an area of active debate in the myeloma field because, ahh, the primary indication for autologous stem cell transplant in the U.S. is multiple myeloma. And the reason why we don't routinely perform allogeneic transplants like we do, for example, in acute leukemias is that each individual cancer has its own biology and sensitivity to treatment, and it seems as such that in multiple myeloma, these patients are much more sensitive to the toxic effects of myeloablative chemotherapy and graft versus host disease, which are complications of an allogeneic transplant that we don't see in autologous transplant.

Now, it is worth noting that, in some instances, myeloma has been shown to be cured by an allogeneic transplant. It's in the minority of instances, but there is a chance of curing myeloma with an allogeneic transplant; however, we still do not routinely perform this upfront, ahh, in the majority of patients with myeloma because of the increased risk of what we call "non-relapse mortality" or mortality related to the procedure itself. That being said, you mentioned, you know, a 20-year-old multiple myeloma, or someone who's much more fit, may have a better shot at tolerating this procedure. In addition, patients who have higher risk disease based on the genetics of their myeloma, may be better suited for an allogeneic transplant based on a variety of factors that goes into determining if they would even be a candidate for this. That being said, an allogeneic transplant should really be considered in the context of a clinical trial, if possible, and a patient should meet with a transplant specialist to have an objective conversation about whether they think their disease would be most sensitive to an allogeneic versus an autologous transplant.

Alicia: Another hot topic that I think a lot of people are discussing when it comes to multiple myeloma is minimal residual disease. What is that Doctor?

Dr. Braunstein: Sure; that's a great question and another hot area of debate in myeloma, so you are touching on all the right areas of debate. Minimal residual disease is essentially whether there is any detectable disease remaining based on more modern techniques that allow us to assess with much higher resolution and much more depth, but whether there is any, you know, residual myeloma cells lurking around. This is something that has been used for many years in other blood cancers such as chronic myelogenous leukemia, or acute myelogenous leukemia, but it is just beginning to come into the spotlight in myeloma partly because our medications are so effective that we're moving the goal post to try to achieve deeper responses, which we know lead to longer remissions and longer survival. So, minimal residual disease in some respect, is a surrogate marker for expected survival. So, if you can achieve absence of minimal residual disease, which is detected by either a technique called "flow cytometry" which looks at the markers on cells and it can really look with higher resolution whether there is any residual myeloma in the bone marrow, or something called "next generation sequencing" which looks at the specific genetics of that patient's myeloma before and after treatment. It can also detect any residual myeloma with a resolution of about one in a million cells. And so, if you can achieve that level of depth of response, it's thought that one can have the longest possible remission. Now, how we use that information, how we standardize the assessments, is a work in progress, but more and more, clinical trials are using minimal residual disease as a regulatory end point for how we assess the response of myeloma patients to novel therapeutic agents.

Lizette: Because you mentioned, you know, the word "cure", with the allogeneic transplant and we are hearing the word "cure" more and more associated with MRD, minimal residual disease, and other indications, but we have been hearing it more and

more also with myeloma, because of these newer treatments. Now, myeloma is a chronic disease. It usually does tend to come back so we haven't really used the word "cure", but we've been hearing it more and more with MRD. What's the field saying about that?

Dr. Braunstein: Sure; and that's really exciting, I have to say. I mean, to talk about cure in myeloma would have been unthinkable 10 years ago. And so, what I explain to my patients is that, you know, again, myeloma is more of a marathon than a sprint. You may have periods of long remission and periods of relapse and we try to get patients back into remission with novel agents, but it's still considered overall to be incurable although patients with lower risk, lower stage disease, may derive a very long, almost decades long remission potentially with therapy. So, the question is what is the definition of minimal residual disease? Is it one in a million; one in a billion cells? And so, depending on how much we move the goal post, currently limited by how sensitive our techniques are, how much we move that goal post determines the depth of response. And that's why it's an area of debate because we're not exactly sure how to define minimal residual disease and how to use it to make clinical decisions. For example, if someone achieves MRD negativity after their induction, do they need an autologous stem cell transplant? That's an area of debate. So, I try to explain to my patients that the first step towards curing an illness is making it into a chronic disease and then refining the treatments and trying to cure it so that patients have the longest possible remissions. but I think cure also entails having a good quality of life during that process, too. So, not only are we prolonging the period of remission for our patients, but they are also having better quality of life.

Alicia: Speaking about improved the quality of life, what's the importance of supportive and palliative care during the stem cell transplant process?

Dr. Braunstein: Yeah; that's a great question because I think, palliative care sometimes has a negative connotation people associate with end-of-life care or hospice care, or the end of the road for their treatment and I try to refer to it as supportive oncology. And, you know, at my Institution, we have a very close relationship, both in the out-patient and in-patient setting, with the palliative care division. These are doctors that have trained in medicine and then did Fellowship training in taking care of patients who have, you know, serious illnesses or may have, ahh, ahh, side effects of the disease itself, such as pain, fatigue, things like that. And so, these are doctors who help co-manage our patients. Now, palliative care, historically, has been very involved in people with, metastatic solid tumors, like metastatic lung cancer, metastatic breast cancer, to help support these patients and literature on those patients, for example, with metastatic lung cancer have shown that palliative care co-management of the patients with an oncologist has actually prolonged survival. The reasons for that aren't exactly clear, but that's what the data show. Now, patients with blood cancers who have just as many symptoms and side effects of patients with solid tumors, you think they would benefit as much from, palliative or supportive oncology care, yet they tend to have the fewest number of consults to a palliative care service.

There have been studies done, particularly in a setting of autologous stem cell transplant that showed that integrating supportive oncology specialists into the care of patients undergoing stem cell transplantation can make serious long-term improvements in terms of their quality of life, their anxiety, their stress level and their long-term integration back into their life. we really try to work closely with the palliative care service to help co-manage our patients and improve their symptoms.

Alicia: I think it is very important to understand that because I know, even for me, when we heard—when our doctors introduced the term “palliative care”, we thought the same thing. We were thinking, she has so much fight left in her. We don't need to talk about that yet. I mean, we automatically thought end of life so I think it's very

important to share that message and allowing patients to understand that it really is supportive in helping them alongside their survivorship.

Dr. Braunstein: It is and, you know, we try to take as much time as we can with our patients whether they're in the hospital or in the office, but there is only so much time, and/or they may forget to voice a symptom such as pain; and the palliative care doctors are very highly trained and expert in managing symptoms that patients with multiple myeloma may have such as unremitting pain, or fatigue, or decreased appetite, or decreased quality of their sleep. So, oncologists are certainly skilled at managing those symptoms, but it can be helpful to integrate a palliative care doctor to help co-manage the symptoms and, sometimes, create a regimen that's more creative and take more time with the patient to kind of iron out those details about which, you know, for example, pain regimen may be best suited for that particular patient.

Lizette: Absolutely.

Alicia: And, Doctor, would you be able to define, just for our listeners, what's the differences between palliative care and hospice care?

Dr. Braunstein: Yeah; that's a great question. So, palliative care does not equal hospice care. Palliative care is, demarcated by clinicians who work as a team to co-manage patients who are dealing with serious illness and involving the family and the community of which the patient exists in their care, as needed, to provide improved outcomes. When the treatment for a particular cancer, for example, has proved futile or the patient is no longer in condition enough to tolerate further treatment; or the patient, themselves, have decided that they would like to change the goal of care from trying to suppress the disease to suppressing the symptoms only, then they may be a candidate for hospice. And essentially, hospice care is considered to be end-of-life care where patients may have less than 6 months expected survival. And that can

take place at home, where a visiting hospice nurse, who is specialized in caring for this category of people who are taking more of a palliative supportive approach than an approach to specifically treat the underlying disease. These nurses will come in for several hours a week and help manage any symptoms to prevent people from having to come to the hospital. And then, there is in-patient hospice, which is really designed as a comforting, supportive environment for people who really wouldn't be able to be symptom-free at their home. And I think the majority of our patients who are candidates for home hospice prefer home hospice since that allows them to be with their family in a more comforting setting and spend some good time with the time they have remaining, you know, with their loved ones.

Alicia: Absolutely; it's so important to note that, just because someone agrees with palliative care, it doesn't mean that they're giving up, the goal of palliative care is to make you comfortable and to help you achieve the best quality of life; and I think it is also important for patient's to know that it is not a siloed field a palliative doctor coordinates care with your other doctors and helps you navigate, you know, the very complex healthcare system that we have.

Dr. Braunstein: Yeah, it is worth noting, too, that we sometimes don't appreciate the toll of a cancer diagnosis takes on the family or the primary caregiver. And, integrating the palliative or supportive oncology can help address their concerns, too, that we may not, otherwise, have time to address in a standard office visit.

Alicia: Absolutely.

Lizette: That's true. It actually, you know, we talk about quality-of-life issues for patients, but it actually also brings up the quality of life for caregivers, too.

Dr. Braunstein: Yeah, and that's really important. I mean, studies have actually shown that they can have just as much distress as the patients in the long term. So, it's important to try to address their needs as well.

Lizette: Definitely.

Alicia: And, for those listening who would like information about resources available to family members, or caregivers, or any supportive person, you can visit www.lls.org/caregivers for all of our resources that is available from LLS.

Dr. Braunstein: Yeah; those are really valuable resources.

Alicia: Thank you, Doctor. Is there is anything else pertaining to this episode that you think we haven't addressed?

Dr. Braunstein: No; just to reinforce that it's important to build a relationship with your oncologist. Sometimes patients come to me for a second opinion or see me for the first and request a second opinion, which we always support. We want our patients to feel comfortable and feel like they're getting the best quality of care that they could get anywhere in the world. And so, I think that starts with building a strong relationship with the patient and their family.

Alicia: Absolutely. We couldn't agree more.

Lizette: Yeah; definitely.

Alicia: Well, thank you so much for joining us today, Dr. Braunstein, on this episode. And thank you, again, for all you do for myeloma patients. We hope to speak with you again in the future.



Dr. Braunstein: Thank you, Alicia and Lizette. This has been a blast. Thank you for having me. I appreciate it.