

Oncology Nursing Society Fireside Chat, Part 1 | Physical burden, treatment costs, and other issues

Transcript

Mary DeRome: Welcome and thank you for joining us for today's oncology nursing society daily update, I'm Mary DeRome, Senior Director of Medical Communication and Education at the Multiple Myeloma Research Foundation. I'm here in Anaheim, California at a national meeting of oncology nurses, known as ONS. This meeting is held every year and it brings together oncology nurses from across the country to present and discuss clinical topics on all cancer types, including multiple myeloma.

I'm excited to be joined today by our Patient Navigation Center nurses, Grace Allison, Brittany Hartmann, and Erin Mensching. They've been attending many of the sessions and will summarize key points about myeloma that they've learned.

When we educate patients and their caregivers about myeloma, we tell them that treatment is for life. It's a chronic disease for many patients. Because the nature of myeloma is to respond to treatment and then relapse over time, patients will not only be on treatment for life but also exposed to many different treatments. This can take a toll on patients physically, emotionally, and financially.

Erin, I'm going to start with you. Based on what was covered today, what can you tell us about the physical demands of a patient with myeloma, both treatment and myeloma related?

Erin Mensching: As we know, myeloma is associated with a high disease burden. This can translate into decrease in quality of life. The physical aspect of the disease is often the most challenging. As Nurse Navigators, we want to encourage patients and caregivers to speak up about each and every side effect or aspect of the disease, whether it's pain or fatigue.

And these are common or they're very common, so we also urge you as patients to not assume that it's part of the disease and not assume that these side effects are normal. Speak up about each and every little aspect so that they can be addressed. For instance, relating to the physical aspect—whether you're 30 or 50 or 70 years old when you're diagnosed, pain is often associated with the disease or as a treatment side effect. There are tips and tools to help with this. We encourage patients to speak up about this part of the disease.

I also wanted to mention that there is a care team ready to help patients and to recommend that you ask questions about how the care team can help. There are psychologists, nutritionists, and physical therapists, who can help patients regain strength. There are a lot of tips; there are a lot of resources out there.

So we just want to encourage patients to speak up about each part of the disease that's impacting their life.

Mary DeRome: That's great advice.

Grace, what was discussed at ONS that might help address some of these treatment- and disease-related burdens for patients?

Grace Allison: One of the most important parts that we learned about this week is communication. Communicating with your physician, and when you go in and see your care team and they ask you how you're doing, it's not a virtue to say "I'm fine." Because it doesn't benefit you and it doesn't benefit the treatment team. They want to know how you're managing on the treatment that you're undergoing so that they can maximize its impact. If you didn't communicate when you're struggling, it might get to a point where they're not able to intervene and manage. Then the treatment might be stopped prematurely, and you don't get the benefit.

A lot of times drugs have to be tailored to a myeloma patient's disease. If you come off one prematurely, it may impact you long term. Have that conversation and let people know how you're doing, so they can give you ways to manage it, that's important. Being open.

Mary DeRome: Brittany, what can you tell us about some of the therapies that multiple myeloma patients take frequently and some of the side effects that they get from these medications, and how patients can deal with that?

Brittany Hartmann: A lot of treatments can cause nausea; that's a big complaint within the community, a big side effect that can interfere with day-to-day life. To go off of what Grace was saying with being open and speaking with your physician, with these medications, that's something that you don't want to deal with every day.

One of the sessions presented a case study where instead of just stopping the treatment altogether, they did an adjustment for taking the anti-nausea medication about 30 minutes prior. The patient was able to stay on therapy. Instead of having to change to a whole new line of therapy, these supportive care measures can help a patient remain on something that is working. I know a lot of patients are on multidrug regimens and are concerned about starting another medication to combat a side effect, but there are other options.

In one of the preventing treatment toxicities talks that I went to, the nurse had piloted on an inpatient unit actually utilizing peppermint oil as an anti-nausea regimen, and it was shown to be effective. They're actually utilizing it and continuing to use that on their unit.

Mary DeRome: That's interesting.

Grace Allison: In our hospital, we had a nurse who trialed it. It was similar to the nausea that pregnant women were experiencing, so they had these acupuncture points on the wrist. We trialed these fans that put pressure on that acupuncture point, and they were successful. Instead of a drug therapy, using complementary approaches and just being creative. Nurses are very creative when patients are suffering, and they want to find ways to help that may not be drug related.

Mary DeRome: I know that many times when we hear from patients, one of the main side effects that they talk about as being very debilitating is neuropathy. And I know that there are some things that can help with neuropathy—a dose reduction, taking a drug less frequently. But what else can work?

Grace Allison: Speaking with your physician, letting them know that you're having this problem; sometimes it can be related to other conditions. We heard a speaker who described a patient who had multiple myeloma but also had diabetes. It was, “what is contributing to this, are we able to better manage the blood sugar levels, better management of the diabetes, would that help?”

When you start experiencing peripheral neuropathy, it can present in many ways. It can be just tingling or numbness, but it also can be painful. Drugs are useful, but there are also complementary approaches. We saw somebody who was using essential oils in the session, they were using frankincense.

We've heard of physicians allowing patients, if it works for them, to try B vitamins. Acupuncture has been mentioned as successful; I've had some people say that that's worked for them. Constantly communicating with your team, asking them about the dosage adjustments, but also seeing what works for you as a person. Exercise was brought up, and they said that it may seem counterintuitive when you're in pain, but having that exercise going on every day increases the blood flow to the nerves so that you do find an improvement. Improvement in the patient's well-being overall, so that was brought up, I thought that was very interesting.

Mary DeRome: Would the procedure be for a patient who was experiencing these symptoms to try something and see if it works? Then, if it doesn't work, try the next thing on the list kind of thing until they find what works for them? Because I'm sure not everything works for every patient?

Grace Allison: Exactly.

Brittany Hartmann: A lot of times, what I've seen done in practice, is actually as Grace mentioned—it could be myeloma, it could be something like diabetes—is to treat the source. You don't want to just mask it. You can ask your doctor about doing a neuropathy panel. There are blood tests that can show if it is some sort of vitamin deficiency and you just need to take a supplement. Or just investigate it a little bit further, but sometimes these are trial and error and a combination of things, not straightforward as though you're just going to take a medication and it's going to go away. Rather than that, you can use some complementary things, increase your activity, and just approach it overall.

Mary DeRome: I would imagine this is important for patients especially if they're on a therapy that seems to be working for them—that they control and mitigate these side effects so they can remain on that therapy.

So not only is there toxicity and effects of the disease and the treatments, but there's also financial impact of some of the myeloma treatments.

Brittany, can you explain to us what is financial toxicity? Is this a new term?

Brittany Hartmann: Financial toxicity is something that has just recently been investigated as part of a disease process. Not only are you dealing with these medications—which are very costly—and having to deal with your insurance providers, but there's other factors such as how often do you have to go to the doctor? How are you managing transportation? Are you local to your treatment center? There are a lot of things to consider. Luckily, there are a lot of organizations that offer grants; they're usually donation based, so they can change time to time.

The good news is that there have recently been generics for both lenalidomide and bortezomib, which are typical for first-line therapy. We're hopeful that that will help with the financial burden for patients. In one of the sessions, one of the presenters mentioned even reaching out to your community. For example, the church did fundraising for a patient. Utilizing all of the possible resources, speaking with your insurance provider—social workers are a great resource at the hospital and can sometimes guide you towards local funding, things that on a national level we may not be aware of. Knowing how to utilize your resources all around you can make a big impact.

Mary DeRome: It's important for patients to speak up to their care teams, speak to social workers, find out who has the information that they need, and then go to those folks and find the resources they need that relate to their financial situation.

Brittany Hartmann: Yes. And as Erin mentioned, the care team is not just the patient and the doctor. It's a robust network of individuals that can help. Knowing who to go to for different things will help patients get the most out of their treatment and improve quality of life overall.

Mary DeRome: Let's switch to another topic that was the focus of a session that you attended called Disparities in Multiple Myeloma With African Americans. We know that the Black community is at a higher risk of developing a myeloma precursor condition, and that multiple myeloma is twice as common and twice as deadly for Black patients compared to patients of other races.

I'm going to start with you, Grace, what are the disparities in diagnosis and care for Black myeloma patients and why do they exist?

Grace Allison: Some of this originates in the history of how Black and Brown people were treated in the medical community, which created this level of mistrust. We have found that Black and Brown people do not access care as readily, so they delay going to see a physician even though they have complaints. Access to care can be more challenging, also. What we at MMRF believe is that every patient with myeloma should receive maximum therapy for a good outcome. Raising awareness is important in the

African American and other communities, letting people know that bringing to your physician's attention—early—issues such as pain prevents people showing up with advanced disease, which is harder to get ahold of, harder to manage, and harder to treat.

So raising awareness is important and having an accurate representation of them in the community overall, that's important.

Mary DeRome: Studies have shown that there are certain therapies that Black patients are less likely to receive. Can you elaborate on that?

Brittany Hartmann: One specifically is stem cell transplant. The outcomes for patients if they do access care is very similar: Black patients and White patients respond, sometimes actually Black patients have better outcomes, even. It's important for patients to be educated and know that stem cell transplant is still a research-based, very great option to get patients into a deep remission, especially upon induction therapy.

One of the things that is sometimes limiting with that is the ability to actually move forward with the transplant because of a lot of different factors. Having a caregiver is a very essential part of the stem cell transplant process. The session I attended that it is not only the that may need to be out of work for 3 months, typically, but you also have the caregiver, who has to cover the additional finances, getting the patient to these appointments, being there to care for the patient, and doing the things that the patient is not able to do him- or herself.

That is one of the limitations that they did mention on stem cell transplant. Again, utilize resources, speak with the social worker, make sure that you are bringing a caregiver to your appointment at the initial appointment. Whenever you can have support there, it's important. It's good for people to know that stem cell transplant, though it can seem intimidating, is still an option.

And patient outcomes are much better.

Mary DeRome: So still seen as standard of care.

Brittany Hartmann: Yes.

Mary DeRome: Erin, what can you tell us about clinical trials and the Black community? I've heard a lot of physicians say lately that now not only is stem cell transplant the standard of care but clinical trials in myeloma can also be seen as a standard of care, especially for patients who have run out of other options. What can you tell us about African Americans and participation in clinical trials and how now important that is?

Erin Mensching: African Americans are underrepresented in clinical trials. We'd like this to change, because to give good data and good information representative of the population, we need more African American participation.

Historically, there has been a mistrust of the medical community and so I just wanted to point out a couple facts about clinical trials: once a patient consents to join a clinical trial, he or she is very carefully monitored. Not only that, but the patient has earlier access to important treatments that are coming out and can speak up about their side effects, and this information is all collected. It's all important information to help these treatments become approved. I just want to reiterate, too, that there is a misconception that there is a placebo involved and with these trials; there isn't. We hope that this will change over time so that the data can be more representative of the actual myeloma community.

Mary DeRome: It would be ideal if 20% of patients in clinical trials could be from the Black community, because essentially 20% of myeloma patients are Black. That would ensure that the results of the clinical trials were actually applicable to every myeloma patient.

If you're having clinical trials that are only including one race, the results that come out—whether or not the drug works or not—may not be the same in other communities. That's why it's so important.

Erin Mensching: It was highlighted in a lot of these sessions: research is such an integral part of myeloma. This is how we get these new therapies approved. One thing we've seen a ton is the timeline of treatments starting in the '90s just with steroids. Then the introduction of stem cell transplants, where we are now versus 20 years ago—it's leaps and bounds.

So participation in these clinical trials to get these drugs approved is important to patients now and in the future.

Mary DeRome: I think all myeloma patients should be grateful to patients who have come before them who have volunteered for clinical trials, because that's where all the new drugs come from. Nothing is approved without extensive study and clinical trials, so it's important for all patients to stand up and volunteer for that if they can.

Grace Allison: And to know that a clinical trial is possible at any point along their myeloma journey. You can join a clinical trial at the very beginning, but clinical trials are an option at any point if it's suitable. A physician can have a mind to what would suit you as an individual. But, to your point, they can only postulate that the outcomes are going to be the same for everybody until we have correct representation of the whole community.

Mary DeRome: What can you tell us about the clinical trials and studies that we sponsor with the MMRF and in our Multiple Myeloma Research Consortium, and have we been successful as an organization in recruiting diverse clinical trial populations?

Grace Allison: I believe we have. Our CoMMpass trial represented the African American community very well. We learned a lot of important data from that, and it has been utilized to just build clinical trials around what we've discovered genetics-wise and

otherwise. We had 11,050 people enrolled in CoMMpass worldwide. That information is going to be very beneficial right now and also in the future.

Mary DeRome: Yes, and that trail has spawned over 100 publications to this point and still going.

Erin Mensching: And it's still referenced in the studies, it was referenced in the session that we attended, too.

Mary DeRome: Great. I think that we at the MMRF are trying to do our part in making sure that we're enrolling a diverse patient population in all the trials that we are involved in, because part of our mission is to find new therapies and potentially a cure for each and every myeloma patient.

Ladies, my last question to you all is, what will be some of the main messages from what you have learned so far that you'd like to share with patients who call into the MMRF's Patient Navigation Center? Grace, I'm going to start with you.

Grace Allison: I believe we should let every patient know that communication is key. Letting them know that we are here to help them weigh the pros and cons, and sometimes we have more time to help them discuss what the physician has proposed as a treatment plan. But we want the patients to be informed, we want them well educated and able to make the decision for themselves. Because sometimes there are multiple treatments that could be suitable, so they be given options that they have to pick between.

We want patients informed, we want to be able to provide information, and we want to be able to have that open communication considering every aspect of their life. It's okay to consider whether you want to go into the treatment center once a week versus three times a week. It's okay to say I want to get ready for my son's wedding, I need to be able to take off for a vacation. All of that is life, and we want the patient to be able to live his or her life—not to be governed by the therapy for myeloma, but able to live with the disease and be happy and have a good quality of life, that's important. Keeping that open line of communication, I think, is very important to be able to accomplish that.

Mary DeRome: So, Brittany, what is your overarching vision from what you've seen so far that you want to share with patients?

Brittany Hartmann: I think that one of the most exciting things is all of the new options for therapy.

I know we spoke about the timeline of where myeloma treatment was 20 years ago, so things such as BCMA therapy and CAR T—which we're going to attend more sessions and learn more about—these are exciting things that patients hear about. We're here to help educate them even more on what their options are. One of the sessions actually said that once you get to the point where you have relapsed or refractory disease, which is an anticipated part of myeloma, you look at all of these options and say, where do I even start? But that's an exciting thing for patients, because one of the anxieties that

patients have a lot of times is knowing that this is a chronic condition. But we want to shift this to, this is a chronic condition that you can live with and that you can manage with treatment as long as you're speaking with your medical provider and making decisions that fit you as an individual patient.

Mary DeRome: Erin, I'm going to give you the last word.

Erin Mensching: One of the nurse myeloma experts said that, so often, patients will come in and say, "I'm fine." I just want to empower patients to ask their questions and maybe even to walk in with a list of questions and say, "I have three questions today; can we address these before we move on?"

Also, utilize a caregiver or, if you don't have one, bring in a friend. Because they can often digest information that you as a patient maybe cannot. Also, weigh the pros and cons with a friend in addition to the Navigation Center. We're here, but also having these discussions with a family member or caregiver is helpful, too.

So utilize the whole care team, ask questions, speak up about any issues, and know that we're here too as a Navigation Center.

Grace Allison: As a whole, the myeloma community is just amazing, they support each other so well. There are support groups that people join, and patients with a new diagnosis are able to get the benefit and the wisdom and hear the stories of the people who've gone before. Know that there is hope, know that there are therapies, know that there are ways of living with this disease. The myeloma community is just amazing; they are resilient people. I'm just so in awe of them.

Mary DeRome: I'd like to thank Grace, Brittany, and Erin for joining me today during this busy but exciting time at ONS. I'd also like to thank our sponsors, Adaptive Biotechnologies, Janssen, and GlaxoSmithKline.

If you have any additional questions, you can speak directly with Grace, Brittany, or Erin by calling the MMRF Patient Navigation Center at 1-888-841-6673.