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SPECIAL ISSUE • 12.2022

IN THIS ISSUE

CARE FOR CAREGIVERS

A diagnosis may not only affect the patient but their caregiver as well.


20 YEARS OF ADVOCACY

How far advocacy groups have come in the past two decades and where they need to go.

CLINICAL TRIALS 101

What are clinical trials and why are they important for patients?

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A close-up photograph of an older woman with short, wavy grey hair. She is smiling warmly, showing her teeth, and has her arms around another person whose back is to the camera. The person being hugged is wearing a black and white horizontally striped shirt. The background is a soft-focus outdoor scene with green foliage and sunlight filtering through.

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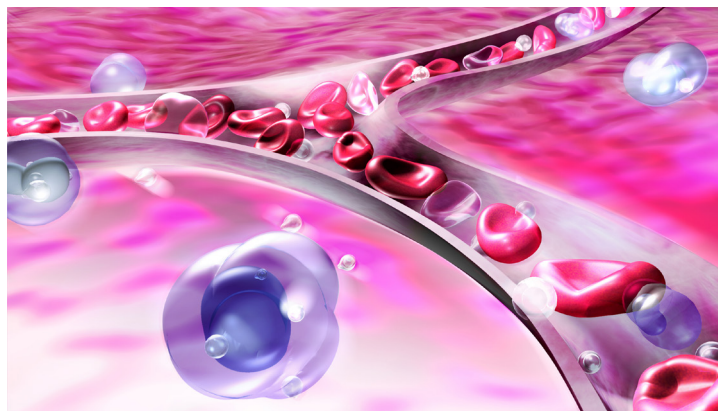
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Contents

MULTIPLE MYELOMA SPECIAL ISSUE · 12.22



CURE® TURNS 20

2 A Work in Progress

The past 20 years have brought great advances to advocacy groups, helping to improve patients' quality of life. But more work is needed to raise awareness in underserved groups.

CAREGIVERS CORNER

4 Caring for the Caregiver

Caregivers must take care of not only the patient but also themselves, as the diagnosis may affect their mental health.

RAPID REPORTER

6 'The Horrible Game of Chicken'

Some patients are at higher risk of infection, it's critical that they keep their care team up to date on any symptoms.

SPEAKING OUT

7 The Basics of Clinical Trials

An expert discusses what clinical trials entail, why they are important and the gaps that remain.

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A WORK IN *Progress*

The past 20 years have brought great advances to advocacy groups, helping to improve patients' quality of life. But more work is needed to raise awareness in underserved groups.

By COLLEEN MORETTI



AS TREATMENTS CONTINUE to advance in the multiple myeloma space and patients are living longer, it is important that they have resources and support around them — something that was lacking 20 years ago.

Karen DeMairo has been at The Leukemia & Lymphoma Society for 23 years and has witnessed firsthand the advances of many myeloma support groups. DeMairo, who is the vice president of education, support and integration at the organization, said when she started, she didn't fully understand what multiple myeloma was — just as many people didn't. "I don't think a lot of people really knew what myeloma was (20 years ago)," she said in an interview with CURE®. "People are still learning what it is, so I don't think there was as much emphasis on providing support as (there is) now."



KAREN DEMAIRO

support like she did. "Finding support for patients with multiple myeloma 20 years ago was very different than what it is today," she said in an interview with CURE®.

"I'd imagine back then it was quite different than it is now because there are so many options and tools that are available to accommodate one's personal needs during their journey."

Furthermore, education was lacking, so support was hard to come by for patients with multiple myeloma. There was also a limited number of support groups for these patients to join. But today, as treatments for the space have advanced, so have the support groups and resources for patients.

WHAT WAS MISSING?

Twenty years ago, there was a lack of awareness around multiple myeloma, so it was a struggle for those patients to find support, DeMairo explained. "And ... if you don't know about it, how can you provide support?" she explained. "And then the support that may have been available, people weren't looking for it, which I think has now changed."

Jennifer Flowers, a community outreach volunteer at The Leukemia and Lymphoma Society, who is currently in remission from multiple myeloma, agreed and noted it probably wasn't as easy for those patients to find

WHAT WAS FOUND?

Flowers is one such patient who has benefited from the advances of support groups. She received her diagnosis in 2008 without knowing what multiple myeloma even was, let alone the treatment, side effects and effect on quality of life it would entail. An aspect she found comforting when joining the organization during her cancer journey was hearing from others and gaining a better understanding of what to expect.

"Patients like me benefit from support groups by connecting with peers who have traveled their journey and openly share their experience," she explained. "It's very helpful and important. Once (you're) enlightened about the journey you're embarking on, you don't feel so blindsided."

Support groups can also provide patients with educational resources, financial advice, side effect support and much more, which ultimately led to an improved quality of life for Flowers. “Advances in support groups are important for me because they elevated my awareness about the disease and tools available to aid and receive the best care and support to live a quality life,” she said.

DeMairo agreed and added that as treatments continue to advance, so will the resources, education and support that are available for patients. “It’s important for (a patient’s) health that they know these treatments are available,” she noted. “We’re seeing more and more progress in treating patients with multiple myeloma. And it’s important that as they survive the treatments and the disease, we help provide those resources to improve their quality of life.”



JENNIFER FLOWERS

Of note, Black Americans are twice as likely to receive a multiple myeloma diagnosis as individuals of another race. “We are not equipped with information to provide support and the best possible tools and care we need to navigate the process,” she said.

DeMairo explained that The Leukemia and Lymphoma Society has been doing its part to help combat the disparities in multiple myeloma care with their program, Myeloma Link. The goal is to increase access to education on and treatments of multiple myeloma to empower Black patients with multiple myeloma, caregivers, survivors and family members. “In terms of support, we, as an organization, must try to reach communities that are most at risk,” DeMairo noted. “And people in general, to make them more

aware of the disease and the resources available to them.”

Although there is more work to be done, what has been done so far has benefited many, including Flowers. She said joining a support group gave her a sense of hope, and she feels grateful to be helping those who are now in a position she once was in. “For me, to make a difference, you have to be the difference,” she concluded. “With that, you give (patients) hope and help in providing the necessary steps they need to take so they can get the best quality care they possibly can.”

WHAT STILL NEEDS WORK?

Both DeMairo and Flowers noted that although awareness around the disease is greater than it was two decades ago, more is needed — specifically in minority and underserved communities. “(Although) we continue to work toward educating others about the disease, there is an inconsistent lack of knowledge about the disease being spread in different communities (because of) our social economic background in the area we live in,” Flowers said.

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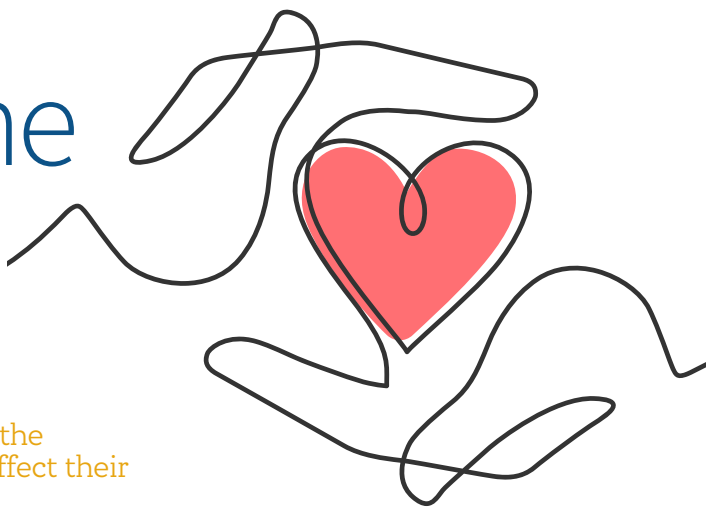


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Caring for the Caregiver



It is important that caregivers take care of not only the patient, but also themselves, as the diagnosis may affect their mental health. By COLLEEN MORETTI

CAREGIVERS FOR PATIENTS WITH

multiple myeloma may experience high levels of stress and anxiety as a result of forgetting to care for themselves during the cancer journey, according to recent study results.

"The reason we did this work is that there is a lack of research into what the caregiver experience is like in multiple myeloma," Dr. Elizabeth O'Donnell, lead study author and assistant professor at the Dana-Farber Cancer Institute in Boston, said in an interview with *CURE*®. "Multiple myeloma is an incurable blood cancer ... and most patients are treated for, on average, seven-and-a-half years or more. But as a result, the burden of being treated for myeloma can be quite significant both for patients and caregivers."

The study, which was published in the journal *Blood Advances*, included 127 caregivers for patients with multiple myeloma. The rates of clinically significant anxiety, depression and post-traumatic stress disorder were 44.1%, 15.8% and 24.4%, respectively.

Compared with patients with multiple myeloma, caregivers reported higher rates of clinically significant anxiety (22.5% versus 44.4%). "These results mean

having a loved one who has a diagnosis of multiple myeloma and is going through therapy does impact the caregiver's quality of life and emotional well-being," O'Donnell noted.

This is true for Marsha Calloway-Campbell, from Cincinnati, who has been a caregiver for her husband since he received his diagnosis of multiple myeloma in January 2017. While her husband was in the hospital during diagnosis and treatment, she rarely left his side, which significantly affected her quality of life.

"As the caregiver, the diagnosis was devastating," she said in an interview with *CURE*®. "I had to think in a moment, 'OK, I'm his caregiver (and) his advocate, (so) I need to stay in this hospital every second.' That was the pressure I put on myself."

Calloway-Campbell was worried she couldn't walk out of the hospital room because a doctor may come in to give them news; she knew nothing about the disease and didn't want to miss a moment. Like many other caregivers, she also had to worry about finances and telling their daughters, but eventually she was able to cross that off the list.

What she did do every day during a monthlong stay in the

hospital was cry. But eventually, she crossed that off the list too. "I would cry daily for him," she recalled. "But I had to stop crying at some point. In my mind, there was a lot of self-talk: 'Marsha, you're sitting here crying, (and) that's not helping anything.'"

She began to use her experience as a lawyer to help her through, and she would think of her husband as a client. When her clients came to her with an issue, she didn't cry for them. "For me to get through, I had to put myself on survival mode and act as a lawyer so I wasn't falling apart every time somebody said something to me about his disease," she said.

HOLDING ON TO HOPE

Although Calloway-Campbell had a hard time understanding the diagnosis, she knew what it would take and what the prognosis entailed. She understood it was an incurable disease because a friend of hers, who is her primary care physician, explained it to her before the diagnosis was definitive. "She was able to give me some information at the time, and I remember her saying to me, 'It's incurable, but it's treatable,'" Calloway-Campbell said.

However, not all caregivers can accept the prognosis. Although

most caregivers (84.2%) reported that the oncologist informed them the patient's cancer was incurable, only 50.9% acknowledged it was terminal and 53.6% acknowledged it was incurable.

O'Donnell explained that there can be a variety of reasons that caregivers do not fully grasp the prognosis of their patient. For one, it could be an issue of terminology — “terminal” and “incurable” may have different meanings to some. Another reason could be that caregivers do not want to accept the prognosis because they still hope.

“There is always just hope,” she explained. “Is it a question of by owning it or saying it, are they somehow extinguishing their own hope? I think we need to better understand that piece of prognostic understanding and what that word means to (individuals) when we ask it.”

TAKE TO GIVE

O'Donnell explained that these results highlight the need for caregivers to pay attention to themselves and take care of what they need so they can better take care of the patient. “It is often said that myeloma is a marathon not a sprint, so pacing oneself is a good place to start (for caregivers),” she said. “There are so many (individuals) who mean

well and want to give to their loved one, but you have to have something for yourself in order to give it to someone else.”

However, it can be hard for some caregivers, like Calloway-Campbell, to begin caring for themselves. “I struggle. I struggle with the ‘for me part,’ honestly I do,” she said.

She explained that when her husband first came home from the hospital, he couldn't walk and he needed help to eat, and she was responsible for tracking everything, including his medications and vitals. There was no time for herself. As a result, she forewent self care and lost 27 pounds in four to five weeks.

Although she still struggles, she tries to remember to do things for herself, as her husband, who is doing better now, and daughters have encouraged her to do. She serves as the director of the Black Myeloma Health Initiative at the HealthTree Foundation, which has been like therapy to her.

“What I do for me is hold on to my faith. I stay in prayer. And my work — I love my work,” she concluded. “People don't understand it, they (tell) me I have to get away from it, but my work does help me get through. ... I try to just focus on the task at hand.”



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‘THE HORRIBLE GAME OF CHICKEN’

Some patients are at higher risk of infection, so it’s critical that they keep their care team up to date on any symptoms.

By COLLEEN MORETTI

PATIENTS WITH MULTIPLE MYELOMA

who have secondary immunodeficiencies (occurs when the immune system is compromised because of an external or acquired factor, such as cancer treatment) are more likely to experience infections during their diagnosis than those without. This results in lower overall survival rates and quality of life, according to a recent study.

Dr. Joshua Richter, lead author on the study, explained that the main focus in treatment is on efficacy. However, it is important to focus on how patients will react to certain drugs, because multiple myeloma is a cancer of the immune system and some treatments can hurt the immune system even more.

“As our treatments get better and better, we’re trying to figure out who is at risk for immune suppression, bad infections or having hospitalizations for those infections,” Richter, an associate professor of medicine at the Tisch Cancer Institute in the division of hematology and medical oncology at Mount Sinai in New York City, said in an interview with *CURE*®.

THE RISK

The study, which was presented at the European Society for Medical Oncology Congress 2022, included 4,638 patients with multiple myeloma. Patients with secondary immunodeficiencies (870 patients) had a shorter duration of multiple myeloma and were more likely to have cytopenia (low number of blood cells) or a severe bacterial infection at the start of the study compared with those without.

During the 12-month follow up, the mean number of infections per patient was significantly higher in patients with secondary immunodeficiencies (7.1 infections) compared with those without (4.6 infections). Patients with secondary immunodeficiencies were significantly more likely to contract at least one infection of any kind (58.9%) or one severe bacterial infection (31.7%) than those without (32.1% and 13.5%, respectively).

Because of these infections, patients with secondary immunodeficiencies were more likely to receive anti-infectives during follow-up compared with those without (92.5% versus 58.3%). Those with secondary immunodeficiencies were also more likely to be hospitalized (26.6%) because of infection compared with those without (9.3%).

Richter explained that a patient’s treatment for multiple myeloma can be affected because of their risk of infection. Some patients may become so sick that they will have to stop cancer treatment, as they can no longer take a therapy that will further suppress their immune system.

“We (often) have to sit there (and) play this horrible game of chicken, in which over time, the disease is getting worse, but (the patient) is healing from an infection,” he explained. “But we’re also trying to find the amount of time where we think it’s safe enough to introduce therapy.”

Of note, overall survival (time from diagnosis or treatment start when patients are alive) at 24 months was lower for patients with secondary immunodeficiencies (74.9%) compared with those without (81.8%).

QUALITY-OF-LIFE IMPACT

“It’s basically an increased morbidity that we see, not just mortality,” Richter said. “The patients have to go through more in their journey, and we’re trying to figure out how to minimize that.”

The risk of infection can affect not only the course of treatment but also a patient’s quality of life. The idea of being in a limbo can become a problem for patients mentally, as their cancer is getting worse, but they also have to fight off an infection caused by the treatment. “This takes a huge toll (on patients), that their disease may not optimally be controlled,” he noted.

The lasting effects from infection can also have an impact on quality of life, Richter added. “Even if a patient does get over an infection ... they can have a cough or feel run-down for months or longer,” he said.

WHAT CAN PATIENTS DO?

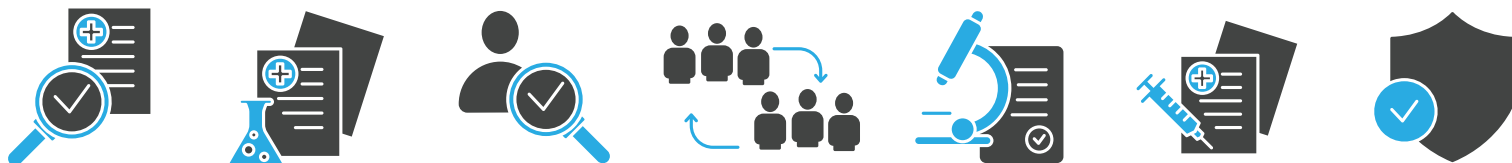
Patients can’t do much to prevent their individual risk of infection, Richter explained, but what they can do is be open with their care team about anything they may be experiencing — small or large. “The biggest thing is to be open with their care team about everything, so that (they) can get a better assessment of how it’s impacting (them),” he said.

Patients should be reporting even common colds they experience to their care team. Richter explained that he doesn’t hear enough about those common colds from his patients, so he doesn’t know to give someone something to prevent them or something bigger that comes from it.

“I always say you don’t get extra points for suffering,” he concluded. “I’d rather (a patient) tell me 10 things that mean nothing than keep one thing that meant something. That’s (often) the tipping point. They had three or four infections that were little, let’s give them something to prevent the big one.”

SPEAKING OUT MULTIPLE MYELOMA

The Basics of Clinical Trials



INTERNATIONAL
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An expert discusses what clinical trials entail, why they are important and the gaps that remain. By COLLEEN MORETTI

CLINICAL TRIALS CAN BE beneficial for some patients, as it may allow them access to treatments they may not have gotten otherwise. And it of course is a step forward for research in multiple myeloma. But what do they really entail, and what should patients know before joining them?

As a part of its “Speaking Out” video series, on behalf of the International Myeloma Foundation, CURE® spoke with their chief medical officer, Dr. Joseph Mikhael, on the ins and outs of clinical trials for patients with multiple myeloma.

Q: CURE®: Can you give us a lesson on clinical trials? And why are they important for patients?

A: Dr. Joseph Mikhael: Absolutely. This is a topic that can be confusing and mystifying to people. Let me try to simplify it. Clinical trials are an opportunity for us to test and evaluate new drugs and new processes to see if we can help the lives of myeloma patients in their quality of life and in their quantity of life. That’s really the goal of all that we do and research, to ultimately find a cure for this disease.

We have three main categories — what we sometimes call phase 1, phase 2 and phase 3 trials. A phase 1 trial is one of the earliest of clinical trials. We typically test drugs in the lab, but phase 1 means we’re bringing it to human subjects. And here, we’re trying to learn how safe the drug is. Usually, we use small numbers of patients, typically patients who have already seen a lot of other myeloma treatments, and we’re testing to see what is the right dose of this drug. (We) know

that this can be very helpful to patients, but we also need to focus on safety.

Phase 2 is when, after we’ve found the right dose in a phase 1 trial, we bring it to a larger proportion of patients to see how helpful this drug or strategy is. We typically give it in a way that we can evaluate how effective is it, how many people is it helping.

And that leads ultimately to a phase 3 trial, which is a comparative trial between the new strategy or drug that we have comparing it to or in addition to the standard of care at the time. So often if we already use drug A, we know it works well and now we’re developing drug B. In the clinical trial, we’ll have drug A as one arm and then in the new arm, we’ll add drug A and B together. Both groups of patients get at least the standard of care, so we’re not giving patients anything less than that. But in that second group, they may benefit from having the additional drug.



DR. JOSEPH MIKHAEL

Q: What is important for patients to know before joining a clinical trial?

A: One of the most important things about a clinical trial is that patients really understand that they are not just being told what to do, (but) that they have a choice in the matter. We conduct clinical trials under very strict and ethical criteria so that we only provide the best we can to our patients, but that discussion becomes really important for patients to understand. Historically, people have been mistreated in clinical trials and it’s a dark mark on our »



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history of research. But now we've really come to a place where we want to do it in the right way for the benefit of the patient. I think it's important for a patient to know lots of things we can discuss, but to (also) really understand what is the purpose of this trial. How could it be helpful, how could it be harmful, what are the potential side effects to know and understand, and how will they be treated through this? How many visits is it going to take, what is going to be involved and what will their potential costs be? More often than not, the costs having anything to do with the trial are covered. But we want to make sure that it's very clear upfront. And a lot of this reflects a good relationship with their health care team so we can have an open discussion.


Q: What are some current challenges in this area?

A: There are always a lot of challenges with clinical trials. One of the good challenges we have in myeloma is that we have so many of them, because we are developing so many new drugs. That's actually a good challenge to have as we evaluate all sorts of different ways to attack this disease. But, as I indicated earlier, there is a history of mistreatment of individuals in clinical trials, and so there is often a lack of trust in the health care system and in research, and that's why it is so important for us to openly and transparently discuss what these clinical trials are about.

Furthermore, we know that in multiple myeloma, in particular, there are certain populations that have really not had access to clinical trials as they should have. Myeloma is twice as common in the African American community. In fact, 20% of all individuals in this country with myeloma are of African American descent — and this is

personal for me because I am of African American descent. Yet typical representation of clinical trials is around 5% to 7%. That disconnect is a challenge that we have to discuss and deal with openly and find very important ways not just to bring up the numbers but to build the confidence and trust in multiple communities so that people can potentially see the benefit of a trial and opt in or out based on their prevalence.

Q: What kind of resources can the International Myeloma Foundation (IMF) offer to help make patients more aware and educated on clinical trials?

A: The IMF has built many resources around clinical trials because this is such a hot-button issue and so many trials are going on. So at our website, myeloma.org, or by picking up the phone and calling the info line, our patients can learn about the basics of clinical trials. They'll get a deeper discussion than I've quickly explained here, what trials may be available near them or what very specific questions they should ask the health care team and what benefits and risks there may be from those individual trials. I think one of the most important things we can do with our patients when it comes to clinical trials is to truly empower them to realize that trials can have a tremendous impact. We've shown for many years that patients on many of these clinical trials have lived much longer than they would have not on the trials, but we want to set realistic and appropriate expectations and do it in partnership with the health care team carefully. 

This article has been edited for clarity and space.



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Margaret Campbell, B.S.N., RN, Winner of 2022 Extraordinary Healer

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