Addressing Health Disparities to Improve the Care of African-American Women Affected by Breast Cancer

FEBRUARY 12, 2014 | PATRICIA K. BRADLEY, PHD, RN, FAAN | TIFFANY P. AVERY, MD
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OPERATOR
Greetings, ladies and gentlemen, and welcome to the Living Beyond Breast Cancer webinar. At this time, all participants are in a listen-only mode. A question-and-answer session will follow the formal presentation. If anyone should require operator or technical assistance during the conference, please press “star, zero” on your telephone keypad. As a reminder, this conference is being recorded.

It is now my pleasure to introduce your host, Katie Creme Henry. Thank you. You may begin.

CATHERINE CREME HENRY
Hi, everyone. Welcome to Living Beyond Breast Cancer’s webinar, “Addressing Health Disparities to Improve the Care of African-American Women Affected by Breast Cancer.” I’d like to thank all of you who’ve taken time out of your busy days to join us. As [our operator] said, I am Katie Creme Henry, and I am the outreach coordinator for Living Beyond Breast Cancer.

The format of today’s program will include a short presentation by our moderator and a discussion with our panelists, followed by the opportunity for you to ask questions. Instructions for how to enter that queue to ask questions will be provided at the conclusion of our discussion.

During our program … [with] our panelists, we will discuss current health disparity data and research, personal experiences caring for [a] diverse community [as well as] strategies on how to make important connections to improve health behaviors and outcomes for African-American women with breast cancer. I’d like to thank all of our speakers for donating their time today.


If you need to leave the program early, or if you joined us late, a podcast and transcript [are] available on our website. You’re welcome to share these with any of your colleagues who may have been interested but unable to join us.

Today’s program-speakers have no financial or commercial relationships to disclose, and there are no conflicts of interest. This program is not sponsored or funded by any commercial or non-commercial entities.

I’m going to quickly introduce you to [our speakers], and then I will turn it over [to them]. Our moderator today is Dr. Patricia Bradley, an associate professor at Villanova University’s College of Nursing. Our panelists are Dr. Tiffany Avery, an associate professor in the department of medical oncology at [Thomas] Jefferson University; Diane Hyman, an oncology nurse at the MD Anderson Cancer Center at Cooper; and Jeanne Chavious, a social worker and the recently retired manager of patient services at Temple University Hospital’s cancer center.

Without any further delay, I’m going to turn it over to Dr. Bradley.

PATRICIA K. BRADLEY, PHD, RN, FAAN
Thank you, Katie. Welcome, everyone, to our webinar. We are very excited to talk today about addressing health disparities to
improve the care of African-American women affected by breast cancer. As Katie told you, our panelists today, our guest speakers, are people who work in the field, or as Miss Jeanne Chavious can say, [people who have] recently retired [from the field]. We’re pretty excited about that for Jeanne. You’re going to get a chance to hear from each of our panelists about their experiences working with African-American women who are affected by breast cancer.

As we go forward today, what we would like to do is to describe to you some of our current health and outcome disparity issues for African-American women. [We’d like] to look at the barriers that these African-American women face in screening, diagnosis, in their treatment adherence and also in continuing their oncology care. We hope to help you understand how the barriers to screening and care have the potential to — if we understand these barriers, we have the potential to improve our patient and provider relationships, as well as our health outcomes.

We would like to describe some of our best practices in overcoming these barriers to care and treatment adherence. We know that understanding barriers to screening and care can improve these relationships, [while also improving] … our health outcomes for the women that we work with.

When we look at breast cancer disparities, we know that breast cancer is the second leading cause of cancer deaths among women in the United States. We also know that breast cancer deaths have been decreasing, and they’ve been going down fastest among white women.

What is happening with black or African-American women? We have the highest breast cancer death rates of all racial and ethnic groups and we are 40 percent more likely to die of breast cancer than white women.

It’s really difficult sometimes to think of a statistic that says that we might get breast cancer less often than [one] group of people, but [in our group, we] die [of it] more often. … We know that when black women come to treatment, or for diagnosis, that they may have a cancer that grows faster and may be harder to treat; that black women often have fewer social and economic resources than other women; and that black women are less likely to get prompt follow-up care when their mammograms [do] show that something is not normal.

We’re trying to look at these disparities and see what it is that we can do to help our women to get into care sooner and … [get treatment for] … any problems. The biggest thing would be if we could bring women in before they have symptoms.

We also know that black women are less likely to get high-quality treatment if they do have cancer. As you look at that, some of these may be patient-related delay in seeking treatment, but many of them are system or institutional barriers to getting care.

For the individual, fear of cancer, the perceived cost of care and the lack of a physician referral are common barriers to cancer screening, as well as other preventative services. What we want to do today is talk a little about how health providers can play that critical role in recommending and increasing the use of the services that are available. We know from research that physicians [who] recommend a patient to get screening are more likely to help this woman to get into screening. They really do believe that when the doctor says, “I think this is a good idea for you and I want you to get this test done,” that women are much more likely to go than not.

Most of this information today is from the [Centers for Disease Control and Prevention] website on health disparities. They have lots of information in terms of different racial groups.

When we talk about breast cancer screening, the primary tools that we use [to] decrease mortality [are] breast self-checks [and mammograms, though these are coming under scrutiny]. … There’s such a controversy in terms of whether breast self-exams do decrease mortality from breast cancer. Today there was something on the news that talked about the study [that said] … mammograms may not decrease mortality from breast cancer — and having a clinical breast exam [was enough to reduce risk]. … Breast self-checks and mammography are two ways that we do know that people can become familiar with their breasts and also be able to check what’s going on. But we’re always having so many different recommendations that are calling women off of using these methods.

What we have found in our work with African-American women who are affected by breast cancer [is that] those who check their breasts or are in tune with their breasts … are much more likely to take their changes to a health provider to check out what is actually going on. They’re also able to ask for a clinical breast exam if they haven’t had one, because they know that it’s important to do. We can help them know where they can get a mammogram and where it is available in terms of not having health insurance or being underinsured.

When we look at the barriers to care, we look from several different areas, looking at social, medical, cultural, spiritual and economic barriers. Many times, people may have some child care or elder care concerns. There may be issues for them around...
the culture of silence around health concerns. There is some information in the literature that talks about African-American women being strong and being silent. Part of the silence has to do with being the provider [in the home], and not wanting to put a burden on others in their families, as well as the silence of not talking about such a stigma as cancer.

We see this often in the African-American community, but it also sometimes is a way for the women to take care of themselves, for that is what they are trying to do. Self-care becomes important, but it also can lead to what we call delay in getting care.

Many comorbidities exist for women in the African-American population. The mistrust of the health care system is something that's a legacy that's been passed from generation to generation. Sometimes it isn't about the Tuskegee syphilis study, which is really the U.S. Public Health Services study. It can be something that's happened more recently in a person's life, or someone that they've talked to, [who] may have been discriminated against in treatment.

Having access to quality health care coverage is an important issue that we know … people with less socioeconomic resources are faced with, many times.

When we look at the role of faith and fate in understanding health status and intervention, what we often see is that African-American women will express that their faith and their belief in God helps them to get the care that they need. Whereas the literature would suggest that people who have fatalism, a belief that they're going to die from cancer — [they] might not seek care. Many times spirituality is a support that helps a woman to get through this trying time.

… We know nowadays, in our economic times, that you could have two people in the house who have an income and it still may not be enough [to cover cancer treatment and the costs it triggers]. … Many times people who take off from work do not get paid for that time. And yet our hours of operation for people to come for screening, for testing, [are] often during [the hours they may need to work]. … People have the financial burden of co-pays and co-insurance. And then there’s always the issue of transportation, to get the diagnosis or to go for care.

We started out really talking from the end of the continuum: of looking at screening and then diagnosis. We are moving along as we look at survivorship issues.

We talked a little bit about the disparities of mortality and morbidity. We know that many times African-American women present — their clinical presentation is more advanced than other groups of women. We know that access sometimes is [about] more than transportation. It’s also attitude within the health care system that might create a barrier for people feeling that they belong to that clinic or to that hospital or to the doctor’s office. Trust becomes an important issue. When you develop trust with your provider, you’re more likely to follow any recommendations.

The fear that we often see is the fear of death, disfigurement, dependency, disability. We also see the fear of discrimination, so we really want to look at those issues as we’re working with women from the African-American community. Then we move along to looking at communication and how important it is.

We’re going to talk in a few minutes with our panelists about the issues of trust and communication and the issue of family and support. One of the areas [about which] we have learned through Living Beyond Breast Cancer’s programs is that disconnection becomes an issue for African-American survivors. Getting connected is an important area of how African-American women live beyond breast cancer. They get connected to God and nature. They get connected to themselves. They’re connected to other survivors, to family members and friends. An important issue that we’re talking about today is being able to be connected to your health care team and to develop that trust.

When we were preparing for today’s presentation, we were thinking about some of the best practices that we know have been helpful in developing relationships with African-American women, in helping them to be connected to the system, to treatment, to care, to their families and to other survivors. The patient-provider communication is an important area where we attempt to build trust. One way we have found is that when a physician encourages note-taking or repeats key points, begins to dispel some of the myths around treatment and outcomes, really to help the individual to have a better understanding of what their care is going to be, that the person is much more likely to stay connected to treatment and to get the care that they need.

Today, Dr. Tiffany Avery is with us. I was going to ask Dr. Tiffany if [she] would be able to talk to us a little bit about some of [her] experiences around the patient-provider communication issue.

TIFFANY P. AVERY, MD

Sure. Well, first, thank you for inviting me to participate in the webinar today. I’m very excited about it.

There’s a lot to say about building a relationship between the patient and provider with a diagnosis of breast cancer. I think,
as an oncologist, I do realize that this ranks as one of the highest fears that anyone has, hearing that they have cancer, and they certainly never want to end up in my office. … Just starting from there, knowing that this is an appointment that no one ever wants to have, I think we need to take extra steps to try to build trust and build communication.

I think what you’ve said are probably some of the most important things, that the provider should really be open to any questions that the patient has, should encourage the patient to ask questions, but should also really teach the patient about their diagnosis. There are different types of breast cancer. There are different stages. There are different treatment modalities, meaning there could be chemotherapy. There could be hormone treatments. There could be radiation. Discussing what types of treatments the patient should have and what the goals of treatment are [is very important, as is] dispelling myths around treatment and outcomes. I think it’s important as a practitioner to cover this information with patients, especially when we first meet and try to build a relationship.

The other thing that’s important is that the provider should really encourage the patient to write down questions as they come up, because, again, patients come into the office and every question they have flies out of their heads. When patients are at home, [it’s good to] keep … a notebook around so that when questions pop up they can jot them down and bring them into their appointments.

The other thing that I think is important — from a provider’s standpoint — is for providers to really be open. If the patients want to seek a second opinion, I think that’s absolutely fine, with cancer patients. A provider open to that, helping [to] facilitate that, is important.

What you mentioned about — or you haven’t mentioned it yet, but it’s on the slide, so I’ll talk about it: communication with patients’ family and friends. When I first meet a patient, the other thing that I like to know is who their support system is. I encourage them, if they’re at their first appointment alone, to tell their supporters which upcoming appointments are going to be most key to have a second pair of ears. Because, again, I would estimate that of everything I say, the patient probably hears only 20, 25 percent. … It always helps to have a second pair of ears, to be there to support [her], to take notes and to ask questions and to step up for [her]. It’s a red flag to me when I see someone who is alone, always. I take that as a door to ask about who [her] support system is at home, who [she’s] told in [her] family or [among] friends, and kind of try to get a support system in place for [her].

PATRICIA K. BRADLEY, PHD, RN, FAAN
That was an excellent segue, Dr. Avery, into talking about that support from family and friends. Miss Jeanne Chavious is here today and has spent quite a bit of time helping family members, helping the patient and [her] family to understand the diagnosis, the treatment, and to get that kind of support. I’m wondering, Jeanne, if you can share some thoughts with us about that.

JEANNE CHAVIOUS, MSW
Thank you. And thank you, Dr. Bradley. I’d be glad to. Yes, over my 20 years of experience in working with cancer patients at the Temple Cancer Center, and volunteering with the American Cancer Society, we found that it’s very, very important to develop that kind of relationship with the patient when [she] first start[s] treatment, as the doctor has indicated. It’s important to have a staff that’s sensitive to the specific needs of the community that they’re serving, so that they can be more effective in their services to the patient.

What we attempt to do when the patient is beginning treatment is to do an assessment … to identify [her] psychosocial needs. … [We encourage her to find someone to] … relate to in the family … [someone who can] … be a support person for [her]. As [people here] know, [after a diagnosis of] … cancer, [the person] … coming into a cancer center … [doesn’t] know what to expect. This is a whole new arena for [her]. When [she’s] going back home and talking to [her] family, [she’s] not quite sure what [she] should be saying to them, or how … [to] say it to them.

In our counseling with those patients, individually, we address with them how [to] … talk to [their family members]. We often will role-play with the patient, assist [her] in … [identifying] the person [she can] … trust within the family system, that [she] can initiate that conversation with.

It’s amazing but it happens too often where [a] patient will say, “I don’t want anyone to know. I don’t want to make [my family] afraid. I don’t want to burden them.” But what we find is that it’s not a burden for the family. What it really does is help the patient and the family as they go through the process of a cancer diagnosis. Women with small children, they have questions: “How can I tell my child? How can I tell my husband?” All those scenarios are individual for that patient. It’s good to talk to them and practice with them [ways to] … do that.

There are tools that you can also use. There’s literature that’s excellent to use with children. There’s material that we can use with the husband … explaining to [the family] what the cancer
diagnosis is. There are things that we can use and that we do use, beginning at the first or second appointment, where we initially start talking with the patient and going through the process with [her], through cancer treatment and up to the point of survivorship. [It is important to] use and develop that relationship with the patient, whether it’s a social worker or a patient navigator or a nurse, whoever that person is that’s working with the patient and supporting [her], and going through the process … of how to talk with the family.

That stigma, that fear of death, is one of the issues that patients are facing. These are barriers to the patient wanting to tell or not, or [deciding] how to tell. We want to make sure that [her] questions and [her] concerns are being addressed. Again, that relationship [with the health care provider, that feeling of] … comfort in talking with that professional is going to be key.

It’s an ongoing process and it’s an individualized process. It starts off one-on-one with the patient. It can go … on with the patient in a group setting. The support groups can be a very important tool to use for some patients. Again, that’s something that may be very new to them. They’ve never been in a support group. They’re fearful of divulging personal things and hearing other people’s problems. But … you can help them to understand what it will be [like], and how nurturing it can be, and how supportive it will be for them, and just ask them if maybe they want to just try it, just observe it …

For some people, it may be more comfortable for them to have … telephone support so they can ask questions about “what I need to say to my family members,” [or] “this came up in the family situation.” There are so many resources available that can help the patient in developing those skills and talking to [her] family and having the family be a support for [her].

The isolation for a patient can be tremendous. That can really impede … progress in … cancer treatment. We don’t want [people] to be isolated. We want [the patient] to be supported. We want the family to understand and to be a part of this whole treatment process for the patient. It [also] helps [the patient] … to understand what [she] need[s] to do in terms of … follow-up for [her] own care. There are so many myths in the community about how you get cancer. I even had a professional person recently ask me, “Well, is this contagious? Can I get it from someone else in my family?” A husband refused to have relations with his wife because he was fearful of getting cancer. There are so many myths out there. The only way that we can address them is to provide patients and families with the information that they need and to answer their questions and their concerns.

These are some of the things that have been very successful in our practice, with that relationship with that patient. Helping … to answer … questions and being responsive … through the process is truly key.

PATRICIA K. BRADLEY, PHD, RN, FAAN
Thank you, Jeanne. For our listeners out there, I don’t know if you’re anything like me. I’m feverishly writing down this information. I’m getting so excited to think about some of the responses or [follow-up] questions that I might have. … For Dr. Avery, I hope that we can get back to this discussion, to talk about how some people are afraid to hurt the doctor’s feelings, so they may not even ask some of those questions. For Jeanne, one of the things that you just mentioned was the issue about family. Sometimes family isn’t just blood relation. It might be church family. I’m really interested to talk a little more about that.

With a good segue into — you were talking about sometimes [support is] … one-on-one and sometimes it could be about groups. Psychosocial support is so important. In the African-American community, some people are really much more spiritually based in terms of involving their spiritual leaders in their care. [I’m wondering] … how we can access those culturally relevant resources you were just talking about … to help husbands and children and to help women as they’re going through this.

How about tailored support groups and support programs? Dianne Hyman, you’re on the line. We’re really looking forward to hearing some of your experiences in relationship to the psychosocial support.

DIANNE HYMAN, RN, MSN, OCN
Hi. Good afternoon. Thank you again, Living Beyond Breast Cancer, for this invitation to join the webinar as well. I’m just agreeing with what was previously said, with Dr. Avery and Jeanne, and then the importance of psychosocial [support] comes into play.

Sister Will You Help Me is a minority, African-American support group [that I founded in 2001] here at MD Anderson [Cancer Center] at Cooper. … What I’ve found in dealing with African-American women and breast cancer [is that we have] … unique needs with that diagnosis, and women feel … that they don’t have the support of other minority women, such as themselves. So Sister Will You Help Me was founded here to bring women together to share in their experiences.

Like Jeanne says, some women may not feel that a support group is what they need. But I tailored it specifically spiritually. It has
faith-based — not necessarily a particular religion, but we know in African-American communities, spirituality provides the strength for us to cope. Having the faith-based and the spirituality component to the support group — women just acknowledge the significance of God in their cancer journeys. We know that spirituality is a key aspect of overall quality of life and that psychosocial support — I think it’s important that at any institution where a woman is diagnosed, that some type of distress screening tool may be done initially upon their diagnosis, so we can [be proactive when we] see … where women are in their distress at being diagnosed.

As previously mentioned, as far as communication, we have women who don’t tell their loved ones of their diagnosis because as women, being in our households and always looking after [others, focused on taking] … care of others first, oftentimes [that role] can [cause us to] put ourselves on the back burner. I had one patient in particular who did not tell her husband or her daughter that she was going to have a partial mastectomy until the night before her surgery. It was because of her perspective of thinking that she didn’t want to interrupt her child’s schooling, and that she would be able to deal with this by herself and not need that much support. That lack of education and that trust issue really became [an issue … with] her and her family, because they were devastated that she didn’t share this. … She had come to every appointment by herself. Like Dr. Avery previously mentioned, when we notice that patients are coming to appointments by themselves, that can be a red flag. This particular individual didn’t share with her family.

There was a lot of education that needed to go on here. Ultimately, [once she was] going through chemo and radiation, which she needed, I was able to reach out to her and invite her to Sister Will You Help Me, where she and her husband were able to come out and just see other women, such as herself, who have gone through the journey that she was embarking on.

I think what’s important about support groups is that women can come at various stages, between newly diagnosed to 20-plus-year survivorship. Women still feel the need … to connect and give back to women who are going through the journey that they have gone through.

That spirituality portion is huge in the African-American community. Tailoring support groups for your individual communities is important. I look to Living Beyond Breast Cancer for their Getting Connected information, which is a culturally relevant resource for African-American women. I just think that [communication is] … just so important [in changing] … the lack of education that some of us have in the African-American community. The education is just such an important aspect of their cancer journey, and just the overall continued communication, the trust in your health care provider. I often tell women, “You are the head of your health care team. You have your surgeon and your medical oncologist and your radiation oncologist.” Here at Cooper we also have oncology nurse navigators, such as myself, [who] can help women navigate through the system and get them the resources that they need, and connect them with social work, and connect them with behavioral medicine if the psychosocial need requires that.

I think it’s [important to connect women with] what’s available within the communities and women’s health care systems and [it’s also essential to] … disseminate that information to the women to get them the support that they need.

PATRICIA K. BRADLEY, PHD, RN, FAAN
Dianne, you said something very important when you were talking about the issue of being the head of the team. I think that one of the messages that we’re talking about today is helping women feel that they are partners in their care, that they do have relationships with the health provider as they go along on their journey.

We know that many times we hear about … the perception that breast cancer is a death sentence, and it’s been attributed to African-Americans. Not everyone perceives it that way, but many people know that others think that way. One of the programs that was sponsored by Living Beyond Breast Cancer to begin to have some culturally relevant literature and information, and Dianne, you just mentioned that, was Getting Connected. It’s a booklet that is about surviving and making decisions and getting support and staying connected and living beyond your diagnosis. We’ve been using this culturally relevant resource information in our Delaware Valley area, Philadelphia, New Jersey area, to help women as they’re going along their journey. What we’ve found is that women who are high risk who read the booklet sometimes look and say, “Hmm. The worst thing that can happen to me, in my mind, is being told I have breast cancer, but this is what [breast cancer] could look like.” It sparks an interest in terms of getting connected, and getting connected [with resources, and] to your health care team.

We also know that as women are going through diagnosis, through their biopsies and … visit[s to] the oncologist and the surgeon and the radiation and chemo, they have also used this resource to help them along the way. … We know that [for] survivors — and Jeanne, you mentioned this in terms of wanting to give back — … sometimes giving back is a way of moving forward. I know that there’s a webinar [Paying it Forward: African-American Women Using Their Breast Cancer Experiences to Help Their Communities] … that’s going to
really be talking about that issue, with Miss Novella Lyons, who is a survivor who has done that, just that.

We want to remind people that as you are attempting to connect with women, African-American women with breast cancer, that there are some barriers that we have that may be difficult to overcome. But one of the things is being able to acknowledge that there have been past abuses in the system, [as well as having an awareness of] … what’s going on now to help to stop the abuse. We want to provide education about rights. What rights do you have as a patient … [or] as a patient perhaps who is involved in a clinical trial? … [It’s important to address] people’s perception of clinical trials, [that they may feel they are] being a … guinea pig, and how we can begin to help people see [that] trials have helped lots of people. … Things that we use nowadays, such as aspirin … went through a clinical trial. [It’s important to see] … what resources are there and what are available to you.

The greatest way for us to overcome barriers is to have collaborative relationships. Dianne talked about the healthcare team and how we can all work together. That’s what’s so exciting about today’s webinar, is that we have a physician and a nurse and a social worker, and each of you are coming with your perspectives on how you work with the patients and with the team in collaborative relationships that maybe exist. We also use established referral networks, and so the importance of — Dianne, you talked about the oncology nurse navigator, and I know, Jeanne, that you’ve had experience as well with navigators within the system, at the cancer center where you work, and how important that is to, again, connect women into their treatment.

As we talk about some specific ways that health care providers can help their patients get breast cancer screening and to get care, one of the ways has to do with reminding patients of their appointments, but also tracking the patients and their progress, follow-up tests or treatments, to make sure that they get the care they need. Sometimes we tell a person [her] diagnosis, or we tell [her] we found something that doesn’t look good and we want [a] … follow-up, and then no call ever goes out to the person to see what’s happening that’s keeping [her] from coming in for that follow-up. If possible, assigning a patient navigator is a wonderful system, and it’s a way of staying connected within the health care system.

We want to talk to each patient about [her] risk of breast cancer, the benefits and risk of mammograms, and the right age to start getting mammograms. We want to tell the person where [she] can get it done. Don’t forget that some people may not be able to afford it. We know in our area of Philadelphia, the Delaware Valley, there are places where people can get help. One of the places, Linda Creed Epstein Foundation, offers free mammograms to women who are uninsured and underinsured. There may be something — you can look around in your own communities to see what resources exist. In Pennsylvania we call it the Healthy Woman Program, but in your state it may be called a different name. It’s meant to be a resource to people.

We always have to find out if there are other questions. That brings me back to what I wanted to say to Dr. Avery about the issue of when people are afraid to ask … questions or get a second opinion, because they may be afraid of hurting [the doctor’s] … feelings. Do your feelings get hurt easily?

TIFFANY P. AVERY, MD

No. This is really not about me or about the oncologist. This is about the patients. This is about the patients getting the best care that they can and feeling the most comfortable that they can. It’s really about them. My feelings aren’t hurt when patients get second opinions. My feelings aren’t hurt if a patient comes back and says that they met another physician and they feel like their relationship is better and they want to be treated by that person. That’s absolutely fine. This is about the patient and not about me. People really shouldn’t feel like they’re hurting my feelings, or their physician’s feelings, with any of that.

PATRICIA K. BRADLEY, PHD, RN, FAAN

I was wondering, Jeanne, when women are told that they need to have follow-up tests, how do you help them to get the support they need to … [meet their individual challenges in getting follow-up care]?

JEANNE CHAVIOUS, MSW

Again, that’s working with the physician and having an understanding with the patient. Sometimes we’ll meet with the doctor and the patient so that we’re … clear … that the patient understands the importance of the follow-up testing. We want to make sure the patient understands where to go and how to get there, and that [she has] the ability to get where [she] needs to go in a timely way. If there’s anxiety prior to that, the patient navigator or the social worker can contact the patient prior to the visit, so they can talk … about those feelings … that [she] may be having about having that test done.

… After [she’s] had the test, if the results aren’t [available] at that time, we make sure … the physicians are … getting [test results back] in a timely way. That’s an important piece, that they get their results in a timely way.
One thing I do want to point out, Pat, if I can, is that there are so many resources available for patients. Frequently women will say, “I never knew. I didn’t know.” I really think it’s incumbent upon us, as professionals, to make sure that people know that there are resources available, that there are things that can be done, that they’re not in this alone, so that they can take advantage of what’s available for them. There are so many resources for breast cancer patients. A lot of what’s available has been geared toward the African-American community, such as the Getting Connected brochure. It should be in all the waiting rooms. It should be available [in the treatment area] when a woman is getting her treatment … so that [she] can see and have access to those resources. Living Beyond Breast Cancer has these great conferences. Some of the other organizations have great conferences, and women may not know of them. It’s incumbent upon us to make sure they are aware of what’s available, so that they can take advantage of [the resources].

PATRICIA K. BRADLEY, PHD, RN, FAAN
You bring up an important issue. I want to say again to the audience: We have no financial stake in the programs that we are talking about, but we certainly have a big emotional stake in terms of believing that this is one of the ways in which we connect with our population of people who are in need.

If you don’t have a program in your area, you may be wondering about creating a program. You heard Dianne Hyman say that … she began a support group called Sister Will You Help Me. One of the things that we found that makes a program really successful is involving the community from the beginning. Many times I get called as a consultant, and I get called by a group of people who say, “We have a program and they won’t come.” The first thing that I talk about is the pronouns that are used in that statement. “We have a program for them.” When the community feels that they have a program with us, it’s always much more successful.

We want to collaborate with other organizations. We all have a mission, and our mission is about helping others. We can do it together and practice what [we] preach. Many times we talk about the importance of getting a mammogram, the importance of talking to your health provider. We can do that [better if] we are connecting with the women.

We want to look for teachable moments. There are many times in the community where you come upon a situation where you can help a person understand what is going on with [her] right there. It doesn’t have to be at a support group. It could be in the ladies room. People many times will say, “What a beautiful pin you have on.” It might be a pin of awareness that I have, that someone has given to me, and I’m able to share: “Oh, this came from this organization and they have this wonderful program.” That’s part of, as Jeanne was saying, how do you get the word out? How do you tell the community that there is something that exists?

We always think about including humor and the importance of staying positive. Many times when we do have programs, they’re celebrations. They’re celebrations of life and a life well lived. Even people who are dying from breast cancer many times find support in being able to live in that moment … with others who also have the same thoughts in mind.

We don’t want to forget that we always, as fellowship, we always have food. But we know that when we go into other people’s community, we can’t always tell them what to eat. We have to, many times, show what might be the most healthy thing. Sometimes you do create a program and the women say, “Oh, we’ll get the food.” Out comes the fried chicken and the potato salad and the other kinds of things. You’re saying, “Hey, can we have some fruit salad, too?” That’s the experience I know. Dianne, is that you chuckling?

TIFFANY P. AVERY, MD
No, that’s me.

PATRICIA K. BRADLEY, PHD, RN, FAAN
But, you know, a piece of that is that we held focus groups at Sister Will You Help Me, at the meeting, and we provided food. What was important was that we had to consider what might be healthy, but also good to eat. We looked at salads and wraps and some other things, and we did have dessert. Chocolate was there — one of the major food groups. But the importance of us not telling people what to do, but involving them [and] having them help to teach us what might be the best thing.

We’re at a time when we don’t know if we have any questions out there. People are thinking about things that we’re saying.

CATHERINE CREME HENRY
Well, Pat, it’s Katie. I’m going to jump back in because I think we are ready to open it up for some questions from participants.

PATRICIA K. BRADLEY, PHD, RN, FAAN
I paused because I just saw a question on the screen.
Catherine Creme Henry

I think I’ll let [our operator] give instructions for how our phone participants can get in line to ask a question and then we’ll ask that first question from the Internet.

Operator

Thank you. If you’d like to ask a question on the phone, please press “star, one” on your telephone keypad. A confirmation tone will indicate your line is in the question queue. Press “star, two” if you would like to remove your question from the queue. For participants using speaker equipment, it may be necessary to pick up your handset before pressing the star keys.

You can submit your question via the Web by using the “Ask a Question” feature on the left side of your screen. Thank you.

Catherine Creme Henry

OK. While callers can get in line, we’ll take the first question from the Web. Dianne, this may be a good one to send your way, since you are a nurse navigator. The question is: Do any of your facilities have a nurse navigator? If so, have you noticed any improvements in these disparities or with treatment compliance?

Dianne Hyman, RN, MSN, OCN

Thank you, Katie. That’s an excellent question. Here at Cooper we do have nurse navigators. I am one of two. … We all are disease-specific nurse navigators here at Cooper. For the most part, I believe that there probably [has been] a decrease in compliance [seen lately], because one of my major roles is the follow-up, and I was actually tracking patients from initial biopsy, [from] being told that they have cancer, until … getting in to see the surgeon, or medical oncologist, or wherever that first appointment may be. I’m doing some tracking to see how many days [go by], or what are the [issues] that are [preventing] patients [from] … getting in, in a timely fashion. We’re looking at that independently here at Cooper.

I believe, as a navigator, that is one of my key roles: to ensure that the patient is getting where [she needs] to be in a timely fashion. That would prayerfully decrease that time from diagnosis to initiation of treatment.

Catherine Creme Henry

Great. Thank you, Dianne. I’m going to do another question from online. I’m going to throw this out to the group. We talked a little bit about how, many times, when a woman is presenting with something suspicious and she needs screening, she may have other comorbidities in addition to a possible breast cancer diagnosis. How do you communicate with her about how her conditions may interact with one another? How do you advise her to communicate with her other health care providers?

Tiffany P. Avery, MD

Is this for patients who were diagnosed with breast cancer?

Catherine Creme Henry

Yeah. Let’s say [she has] … been diagnosed and now you’re planning a treatment plan … with [her] comorbidities.

Tiffany P. Avery, MD

There are a few that we need to pay particular attention to for patients who are starting cancer treatments and chemotherapy in particular. [For people with] diabetes, there are some [cancer] treatments that can cause the sugars not to be as well controlled. There are some drugs that can contribute to hypertension, so if a patient is already hypertensive and on medications, or has other conditions [that] have left [her] with any neuropathies, which are numbness and tingling of the nerves, these are all important conditions that could impact … treatment.

When a patient has any of these, I go over [that] with [her], that it’s actually really important to have close follow-up with [her] primary care physician, whoever is managing this [other condition]. Sometimes it could be a cardiologist, if it’s high blood pressure, but usually [a] primary care doctor … is managing [her] diabetes … high blood pressure, etc. It’s important to be in close contact with the [patient] and to let [her] know that these are the kinds of things that can happen during treatment.

I also oftentimes will call and talk to the primary care physician, if someone is having particular trouble with glucose in diabetes, or with hypertension. [These issues are] … included on any of our clinic notes. For example, [the doctor] … would get a copy of any of the notes, so that [he or she is] aware of what the patient is going through and what the side effects could be.

Jeanne Chavious, MSW

Also, if patients have a mental health or a substance abuse diagnosis, we are taught to identify that early on and, of course, have the proper consent signed by the patient so that we can be in communication with those providers and [make sure] that their physicians are aware of that. If the social worker becomes aware of that, [he or she] will communicate that to the physician and the
physician can be in communication with the providers. [Health care providers involved in that care plan are] … aware of the medications the patient is on and somewhat have … coordination of care for that patient.

CATHERINE CREME HENRY
Thanks, Jeanne. I’m going to actually pose another question. We’ve got a couple of questions online that are addressing one of those big issues of financial concerns, the burden of paying for treatment, of the time off work, of child care, of transportation. I’m … looking to Jeanne as the social worker, but I will open it up to the group. What are some resources you have accessed, what are some strategies you’ve employed to help with some of those very real financial obstacles?

JEANNE CHAVIOUS, MSW
That sometimes can be very difficult. Resources aren’t as available as they have been, but there are still some resources available. In Philadelphia, the American Cancer Society does have some volunteer drivers and they’re always looking for more volunteers to take patients to appointments. Whatever their insurance carriers, we look to them to see what else is available in terms of transportation resources. That’s something we’re always dealing with and always are struggling with — finding those kinds of resources.

I know in the past Living Beyond Breast Cancer has assisted some patients with financial matters, with issues of breast cancer. Those are things that we have to look on as a case-by-case basis — locating those resources that are available to the patient.

TIFFANY P. AVERY, MD
Missed appointments, and sometimes it’s medications that weren’t picked up, weren’t used, and then I found out that they weren’t picked up because of financial reasons. There’s a lot that our social workers help with in terms of getting paperwork, like for FMLA [Family and Medical Leave Act] and leaves from work, and that kind of thing up front.

CATHERINE CREME HENRY
Great. Thank you. I’m going to ask one last question because we are almost out of time. But going back to the theme that we had talked about, of how [the] patient really is the head of her health care team — women with breast cancer often want to know what else they can be doing during treatment to support themselves and to improve their health and to take care of themselves. Why don’t we go around and have each of you give one primary recommendation you like to give to the patients that you see.

PATRICIA K. BRADLEY, PHD, RN, FAAN
Who’s starting?

DIANNE HYMAN, RN, MSN, OCN
I can start. Find time for yourself. Also, when someone asks you, “Do you need help?” take them up on it. Oftentimes we struggle with that. “I’ll watch the children for you.” “Can I take you to an appointment?” Sometimes we don’t want to burden our loved ones, but I encourage my women: If someone asks you, take them up on the offer.

JEANNE CHAVIOUS, MSW
This is Jeanne. I was just going to say that I always encourage patients to surround themselves with positive people, people who are going to be supportive to them, [to] surround themselves with people who are going to bring them some joy, who are going to be not discouraging but encouraging to them. The spiritual aspect is so important, to find time for that spiritual part of their life. But surround themselves with those positive resources. That’s so important for someone going through breast cancer.

DIANNE HYMAN, RN, MSN, OCN
I think sometimes, too, that the patient won’t share that. You may just find [out because a patient is] … not making appointments, and you have someone do a follow-up call to just try to figure out what is going on, that [she has] missed [her] last two or three appointments. You may glean that out that there are some issues.
think during your treatment, if you can, and then certainly when the treatment is done, [pay] particular attention to nutrition. … Get the fresh fruits and vegetables into your diet, at least five servings a day [and] exercise. We do have good research that shows the impact that 30 minutes [of exercise], six times a week, or an hour three times a week — so three hours of even moderate walking per week — … and the impact of maintaining a healthy body weight … the impact that has on cutting down breast cancer recurrence, it’s about a third, which is really a lot. It’s huge. I think that that’s something that patients can definitely take into their own hands and really do a great service for themselves.

Sometimes during active treatment, it’s not possible. But certainly after you’re in the survivorship period, start thinking about these issues.

PATRICIA K. BRADLEY, PHD, RN, FAAN

Then I would like to say that one of the things that I’ve heard from survivors — one young survivor in particular was saying that she found that when she was being silent, she felt that she was actually blocking her blessings and not allowing others to be there for her. One of the recommendations that we make is that [patients] do connect with somebody, whoever that is.

Thanks, Katie.

CATHERINE CREME HENRY

Thank all of you, Pat and Tiffany and Jeanne and Dianne. I appreciate you sharing your time and expertise with us today.

…

That is the end of our webinar today. Thank you all for participating and I hope you have a great day.

[END OF TRANSCRIPT]