Multiple Sclerosis Association of America

Intimacy with MS: Understanding Affectionate, Romantic, & Self Love

Presented by:

Evelyn A. Hunter, PhD

Marie LeGrand:
Good evening, everyone, and welcome to the MSAA's live webinar "Intimacy with MS: Understanding Affectionate, Romantic and Self Love" with Dr. Evelyn Hunter. I would like to take this opportunity to thank you all for joining us this evening. I'm Marie LeGrand, Associate Vice-President of Mission Delivery, Health Equity and Education for MSAA and your host for the program.

Before turning it over to our speaker this evening, I would like to take this opportunity to go over a few of the services that MSAA provides, as well as some housekeeping items. Now, as you may know, MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support for the entire MS community. Our services include a national helpline, providing English and Spanish services Monday through Friday from 8:30 a.m. to 8 p.m. Eastern. Additionally, MSAA provides equipment and cooling products designed to improve safety and mobility, and to also help with heat sensitivity. We also offer an MRI access program to help cover some of the costs for individuals with MS who qualify for assistance. We provide a variety of educational programs, including webinars, such as this, and on demand videos, online tools, publication and digital resources that includes the Ultimate Treatment Guide, which is now available on our website. Now, this interactive guide describes and compares 19 FDA approved MS treatments and will help people living with MS make informed decisions and choices. MSAA offers support through community connection to help you stay connected with other members of the MS community and to learn more about MSAA's programs and services, please visit our website or give us a call to speak with one of our specialists.

Now, as a reminder, throughout tonight's program, you will have the opportunity to ask questions by typing them into the chat box. We encourage you to submit questions throughout the program and we will do our very best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and will help us in developing future programing and content. A link to the survey will also be included in the chat box. Please note that this program is for educational and informational purposes only and does not constitute as formal recommendations. Please speak with your doctor or healthcare provider if you have any questions or concerns.

We are extremely grateful to have Dr. Evelyn Hunter back with us, who will provide us with an understanding of intimacy in the cultural context of black and African-American communities, as well as the corresponding emotional engagement that intimate partnerships require. Participants will learn about obstacles and strengths to develop intimacy in the context of multiple sclerosis.

Now, without further ado, I'd like to introduce our speaker. Dr. Hunter is a licensed psychologist in the state of Alabama and received a B.A. in psychology from Emory University and a Ph.D. in counseling psychology from Auburn University. Prior to joining Auburn Psychological Wellness Center, she completed an internship in General and Multicultural Psychology at the Georgia Institute of Technology and a post-doctoral fellowship in health psychology at North Main Counseling and Wellness/Premier Neurology. Her passion is to connect aspects of mental, physical and spiritual well-being. In addition to clinical practice at Auburn Psychological Wellness Center, she is also an associate professor in counseling psychology. Welcome, Dr. Hunter.

Dr. Evelyn A. Hunter:

Thank you, Marie. I'm so excited to be here with everyone today to talk a little bit about intimacy with MS and understanding affectionate, romantic and self-love. I'm going to get started by just giving a couple disclosures and notes. So the views that I'll be talking about today come from, are supported by professional literature and evidence and also clinical expertise. And we'll also be using a Vevox app today. So throughout the program, I'm going to ask you to be interactive and participate with me. And I'll tell you a little bit about how to get to Vevox, that app, in a moment.

So let's talk about what we'll do today. We're going to start by talking a little bit about understanding intimacy, including how we differentiate between the types of intimacy and barriers to intimacy. And then we're going to move into understanding some cultural barriers in our intimate partnerships that really are rooted in black communities and intimate partnerships within black communities. We'll then move into understanding contextual barriers and how we might combat contextual barriers, and the context that we'll share tonight is the context of multiple sclerosis. So we'll focus on multiple sclerosis as a contextual barrier. And then finally move into navigating intimacy in healthy and culturally adaptive ways as we learn about commitment barriers and how we navigate those in the context of partnerships.

So let's jump right into understanding intimacy. Now, before we do that, I'm going to ask you to take a moment to get on the Vevox app, either through your phone or computer. There are two ways, you can use this QR code and it'll take you exactly where you need to go. Or if you prefer, you can go to vevox.app and type in this ID code and it will get you connected to where we need to be. I'm going to move to our next slide, but the QR code and ID are there as well if you still need them. They're in that top right corner. And what I'm going to ask you to do is just type some words in that tell how you define intimacy. So what are some words that come to mind when you think about intimacy? And you can just type a word or two in and press enter. We'll give this about 45 seconds to get a few responses.

I have about 15 seconds left. So if you want to go ahead and type in a word and press, enter. And close our poll.

All right. So we have “love.” “Love” a couple of times “closeness,” “hugs and kisses,” “feeling open,” “nasty time,” which I'm guessing would be sex. I love that one. “Sharing feelings,” “affection,” absolutely. So we're right on track with regard to sort of how we think about intimacy. I'm going to share sort of how we talk about it in the professional literature. But you are right on target.

So intimacy is relational closeness with someone else. So that trust, that openness and that vulnerability. And tonight, we're going to really focus on three types of intimacy. So we're going to talk a little bit about emotional intimacy, which is sort of our transparency and openness in our feelings and our fears and our thoughts. We're definitely going to talk about physical intimacy, both sexual and non-sexual. So hugging, cuddling, kissing are also forms of physical intimacy. And then we're going to talk about intellectual or cognitive intimacy. So this is about intimacy where we're sharing ideas, opinions, our life perspectives and really learning from someone else in a relationship.

Intimacy is a demonstration or a product of that healthy relational love. So when we share the words, there were a couple folks who put “love” there, and intimacy and love are deeply connected, right? Intimacy is really how we demonstrate healthy relational love. And in general, relational love is creative and compassionate and supportive care for another person. And it takes on a number of different contexts. So there's affectionate love where we really support and enjoy relationships. There's bonding, there's esteem-building, you know, folks are gassing you up, shouting you out, and typically targets of affectional love are our friends, our siblings, our parents.

There's also romantic love. Romantic love is often what we think about when we think about intimacy. And that romantic love is compassionate. It's creative. It's often energetic, and the target of romantic love tends to be romantic partners. And then finally, a really important form of love that we often forget, but we don't want to leave off the table tonight is self-love. And self-love is that empathetic understanding for oneself. It's openness and authenticity, so sort of an honest openness with the self. And of course, the target of self-love is you. So as we understand how we build intimacy, what we're understanding is how we better demonstrate healthy relational love to one another.

I love this quote by Nikki Giovanni. She says, “We love because it's the only true adventure.” So true. So we're going to get into talking a little bit about barriers to intimacy so we can understand what's blocking intimacy and how we might combat some of those barriers. And we're going to hit on three barriers tonight. So the first set of barriers, we're going to talk about are cultural barriers and cultural barriers, especially in black communities, are how we learn to be or not to be vulnerable with one another. Then we're going to talk about contextual variables in the context of our lives. So as I shared that contextual barrier we're going to focus on tonight is multiple sclerosis. And then finally we're going to talk about commitment barriers. And commitment barriers are those interpersonal barriers to intimacy that happen in engagement with one another. So let's jump right into the cultural landscape and talk about those cultural barriers.

So first, we have to be honest about the things that we learn, and I'm going to share four cultural barriers to intimacy tonight, but there are many more that often can be rooted in the black community as a whole, but also sometimes in our families. We can have certain cultural barriers that are unique to our own family systems. But one that's common in the black community is that we keep our business in the house. Okay? And this is about, you know, people shouldn't know what's going on with you. And we're often taught that when we're young and growing up.

And unfortunately, it becomes a barrier to intimacy because it teaches us to avoid open or trusting communication with anyone that's not in our very, very immediate circle.

Another controversial barrier that we learn is “don't have no babies.” Or there are lots of ways that this is taught, you know, “keep your legs closed,” “wrap it up,” all of that context. And oftentimes this can be seen as a positive lesson, especially for folks who are not ready to have children or not ready to engage in sexual intimacy. But what this cultural barrier can inadvertently do is avoid acknowledgment of any type of intimacy that's not sex. So we don't sort of understand non-sexual intimacy like hugs and kisses and cuddling. And when we are ready to engage in sexual intimacy, we lack understanding and we lack an ability to communicate around sexual intimacy. So this really shuts down learning how to talk about sex.

The “Strong Black Woman/Strong Black Man” is a strong, strong, strong cultural lesson in teaching that we often have that can be a barrier to intimacy. And this really teaches us that we take everything on our back. You you handle it, you grin and bear it. And it teaches us to avoid vulnerability in our relationships and also to avoid dependance in our relationships. And then the final cultural barrier barrier is “They won't do you right.” And so this is a cultural mistrust that's really been driven by the media portrayal of black communities and black men and women in partnerships. And what it teaches us is to avoid trusting potential partners and can really disrupt intimacy early on.

So we're going to talk about these cultural barriers. But before we do, we need to really understand the relational history in African-American communities so we understand where we came from, so we understand where we're going. And really this helps us to sort of connect with what keeps these barriers in place. So in the early 1800s, enslaved communities were “jumping the broom,” traditionally, to mark, oftentimes, secret commitments during enslavement. And that leads us to 1890s to the 1950s, after legalized marriage for black communities was available, black communities actually had the highest marriage rates in the U.S. up until the 1950s. In the 1950s and 1960s, we really saw the civil rights movement explode and the civil rights movement really highlighted a lot of black love and family in context. So think MLK and Coretta Scott, Malcolm X and Betty Shabazz as great examples. And then in the ‘70s to the ’90s, we saw a lot of popular media showcased black love. So we had Good Times, we had The Jeffersons, we had The Cosby Show, Martin, which led us into the 2000s where #blacklovegoals trended as Barack and Michelle Obama entered the White House.

And then into the 2020s, and the time that we're in now is a time in which black love is actually pretty strong in terms of what research looks at. So about 82% of partnerships in the black community are black partnerships. But the narrative of black love is really rooted in racial inequity. And so there's a lot of a narrative around, a false narrative actually, around the fact that, for instance, black men and women do not get along. Black women are perceived a certain way in black communities, in a negative way, in black communities, in the context of relationship and partnership. Black fathers don't stay in their families, even though research tells us that black fathers are as present with their children as folks of other race and ethnicities. And so we really have strong partnerships in the black community, and there's a lot of media portrayal that suggests that we don't.

And so when we understand that historical context of where we came from and where we are, it helps us to understand how the cultural barriers to intimacy that we learn in our families persist. So, you know, we keep our business in the house because during slavery it was dangerous to expose a relationship. And that's sometimes continues through today, it can be dangerous to expose intimate parts of yourself outside of your house. Black folks and black communities can experience, you know, racism on the job and things like that. And so keeping business in the house has felt protective. The, you know, don't have babies, keep the legs closed, really, again, stems from the fact that in enslavement family formations took really multiple forms. There were a lot of stepfamilies. There were a lot of families that were created because owners of enslaved peoples were dictating who had children with who, and they could often be coupled with painful experiences where families were ripped apart, children were taken from mothers and fathers, etc.

The Superman/Superwoman Complex. We are a community of survivors, right? And so we have learned to survive by sort of not showing vulnerability or weakness on the outside. This is seen in that historical context in our media portrayals, in our #blacklovegoals, where the only acceptable type of relationships, the only relationships we talk about are the perfect ones, right? The perfect black partnerships. And we don't often see vulnerability in terms of talking about struggles in the ways that folks may move in and out of intimacy in the context of a relationship.

And then the cultural barrier of “they don't do right” is also rooted historically. So, you know, enslaved men often were required to engage polygamy by slave owners, and slave women were also often required to bear and breed children independently of their fathers. And so, some of our understanding of intimacy and relationships are rooted historically, and then the current media narrative really incorrectly characterizes current relationships in the black community in a way that really doesn't align with what the research shows it's actually happening in our communities.

So all of these cultural barriers, then, disrupt intimacy and then disrupt the ways that we experience those different types of love. So “keeping our business in the house” makes it really hard to have true affectionate love. You know, the “no babies” makes it really hard for us to talk about sex with our romantic partners when it's time to have sex and that disrupts romantic love. “Superman/Superwoman Complex” disrupts affectionate, romantic, and self-love because we can't be vulnerable with anybody. We fall apart with ourselves because we're taking on so much, and it's hard to be dependent in the context of intimacy. And then “they won't do right” both disrupts romantic and self-love. It disrupts romantic love because we believe we can't trust in a potential partnership. But then it also disrupts self-love because we begin to believe the context of what we hear in media narratives about ourselves, so we begin to believe those negative stereotypes about ourselves.

So I want to bring you back to the Vevox, if you kept it up on your phone, great. But if not, that QR code is in that right corner for you at the top of the slide, you'll see the code. And what I want you to do is just select the cultural barriers that you've noticed in your own life. So were you taught to keep your business in your house? Were you taught that you shouldn't, you know, sex was a taboo topic? No babies, wrap it up, we don't talk about it. Have you adopted a Superwoman/Superman complex? And you can check all of these or none of these. Did you adopt a, you know, black folks don't do right? Or is there some other cultural barrier that you're familiar with? And just check as many as apply. You have about 15 seconds to get your checks in.

All right. So, wow, 75% of us we're taught that we keep our business in the house. We got, you know, 62% were taught that sex is not a topic that we talk about. Superwoman/Superman, about half of us, and, you know, were taught that we can't show weakness or vulnerability. About half of us were taught that we can't trust relationships. And then there's a whole 37% of us that have some other cultural barrier that they're realizing that has come up that may be a barrier to intimacy. So I'll be interested to hear about those during our Q&A and feel free to put those in the chat as well.

So we want to address barriers to cultural intimacy because the absence of intimacy can be dangerous to us. There's a great book that I recommend called What Mama Couldn't Tell Us About Love, and the author of the foreword of that book writes a letter to their mother and it reads, "Mama, you taught me how a black woman could survive and prevail in this world, but only if we are stronger than everyone else... You took me right where I should be so I could learn what I had to do in this world. But the one thing I desperately needed that you couldn't teach me caused me so much pain, that even with your strength, at 64 years old, you lay down to die. You were so starved for love... The one thing worse than being lonely is the ache of living with someone without intimacy."

So how do we combat the cultural barriers to intimacy? The way we do that is to lean into our community strengths that are built into our relational schemas. So Dr. Hunter, What is a relational schema? It's a fancy word, but it just means our thought process, our relational schemas are the thoughts that we hold about relationships and community strengths in the black community especially are all the aspects of relational engagement that are unique to black communities, that are uplifting to black communities and beneficial to black communities. So centering relational schemas that focus on our community strengths as opposed to some of those cultural barriers, it allows us to override cultural barriers in intimacy. So we're going to talk about two of those community strengths that can really combat cultural barriers for us.

So the first is the village mentality. Black communities are interconnected. And what's really interesting, what you see in research is that a lot of folks in black communities have an unwillingness to burden others or to lean on or be dependent on others. But there is a willingness to give support and to have others lean on them. So what we have to remember is that when we center the relational schema of the village that other folks are willing to have us lean on them, it helps us to increase vulnerability in our relationships. And it combats both that, you know, keep our business in our house and that Superman/Superwoman cultural barrier by allowing us to open communication and vulnerability. Right? Remembering that in the context of the village mentality, we are able to lean on one another.

The second strength in black communities to really combat cultural barriers to intimacy is the kinship experience. So the kinship experience are all of those experiences of mutual support and informal exchange. Think, you know, what's happening in your houses with your immediate and extended family, when you go to church, the traditions you hold. And what tends to happen in the context of the kinship experience is that we hear stories and see examples of healthy, intimate partnerships. And so those examples can be sought out. We can seek out individuals or couples or partners or friends in our kinship experience that are engaging in healthy, intimate partnerships. And that really combats the, you know, inability to talk about sexual intimacy or to talk about types of intimacy that's difficult and that folks don't do right. Right? Combats those by helping us move into openness to intimacy and trust. So that's how we combat cultural barriers. And I love this quote: "It is an absolute human certainty that no one can know their own beauty or perceive a sense of their own worth until it has been reflected back to them in the mirror of another loving, caring human being."

So now that we sort of talked a little bit about cultural barriers, let's move into contextual barriers to intimacy, specifically around MS. And so, just a reminder, we're going to focus on these three types of intimacy, emotional, physical and intellectual intimacy. And, MS hits all three of those types of intimacy in different ways. So about 80% of folks at some point report some intellectual or cognitive difficulties around intimacy and multiple sclerosis. But in the context of emotional intimacy, 55% of partners report that MS actually increases emotional intimacy and communication, the context of MS builds something that's connecting for partners. And then in terms of physiological intimacy, about 75% of folks with MS report at some point over the course of MS, some difficulties with the physical aspects of sexual desire and sexual functioning. So we're going to talk about all of those today.

Now, important to remember that intimacy is interconnected, so intellectual, emotional and physical intimacy are connected. And when we begin to address pieces of those intimate barriers, they impact the other areas, right? So you don't have to tackle all the areas of intimacy at one time. The other thing to remember is that barriers to intimacy can impact anyone in a relationship. So that could be the patient with multiple sclerosis, it can be the care partner, it could be a sibling, a child, a close other. And so all of us can work on our barriers to intimacy.

I'm going to talk a little bit about first barriers to intellectual intimacy. So the first is secrecy, you know, kind of feeling like no one can know about my MS or no one can know about my specific symptoms. I can't talk about this out loud. The second is a lack of information. Sometimes we don't know how to talk about our concerns with MS in general or specific to intimacy. Right? What are the words I use? How do I even phrase this? How do I have this conversation? Differences in communication can also be a huge barrier to intellectual intimacy.

So, you know, I'm very extroverted as a person. My husband is very introverted. We are closing in those those barriers to intimacy all of the time in our differences in communication. So maybe one partner is a person who Googles everything and wants all the information, and another partner is a person that wants to know nothing. Maybe one's a talker and one's the silent type. Maybe one partner is a super planner, they're going to leave this session and say, I want to right now the ten step plan to how we're going to improve our intimacy. And another partner is like let's just see how it goes, fly by the seat of our pants. So sometimes we have to bridge those differences in communication.

And then there's also the catch 22. And this is really in the context of new partnerships, affectionate, romantic, where, you know, it feels like I can't really share about MS until I'm really close with someone, but I have trouble getting close with anyone because I don't really share. And so those are barriers to intellectual intimacy, and there are few ways we can combat barriers to intellectual intimacy in MS.

So the first is to improve our communication around topics that aren't as threatening as maybe MS or how MS shows up in our intimate relationships. Oftentimes when we improve communication with loved ones, generally it improves communication across all aspects. We can also write it down. So journaling how we might imagine a conversation could go or how we want it to go can give us a little bit of courage. Help us strengthen our resolve. It can help us identify the really important things that we want to make sure we say. And it can help us clarify thoughts and feelings before we have the actual conversation. And then finally, there are a ton of resources that can help us talk to one another, help us improve our intellectual intimacy. So partner therapists who will see romantic couples, family, siblings, friends, their support groups and communication and trainings. And all of those can be helpful resources to combat barriers to intellectual intimacy.

Now I'm going to move to barriers to emotional intimacy. And there are a number. The first is uninvited mental health concerns. So it's very common to experience anxiety, depression, shame or guilt in the context of multiple sclerosis. And oftentimes our own experiences of uninvited mental health concerns can disrupt our emotional intimacy with others. There's also excessive concern where we kind of become more focused on MS concerns than on engaging emotional intimacy in a partnership. And this is especially true for care partners, where care partners can really dive into really caring about the physical aspects of multiple sclerosis in their loved one and disregard some of that emotional intimacy in the partnership.

Silence is another one, and this is sort of related to secrecy in intellectual, where we avoid connection altogether. We sort of stay silent. We don't say what's on our mind. We don't say how we feel. And then oftentime is misinterpreted by other folks as a lack of concern. And again, this goes for care partners, for folks with MS, for friends.

And then finally, disappointment is a barrier to emotional intimacy. You know, oftentimes, you know, for most folks, MS is not how you imagine things. Sometimes it impacts your partnerships in ways that you didn't imagine. And there can be disappointment that we hold around the way things are changing, the way you're changing, the way others are changing when we hold those alongside how we would wish them to be. And so that can be a barrier to emotional intimacy.

The ways we combat those barriers to emotional intimacy are really similar to the ways we combat barriers to physical intimacy. We want to make time to listen to folks that we're in relationship with. And non-judgmental listening is really action oriented, so we set aside time and space. We focus on what the person is saying. We seek to hear and understand and not respond. So that can really encourage other folks to move into vulnerability with us because they trust that we are willing to hear them. You can also craft a new vision for your partnership to strengthen emotional intimacy. So spend time with your partner or your friend or your loved one, imagining what you want the partnership to look like in the context of MS. You can be creative. You can get excited about the different possibilities of the relationship. What should change? What things should we do? What things can we plan together to craft a new vision for the partnership? And then finally, again, getting help. So therapists, support groups, and psychiatric meds, especially in the context of those uninvited mental health concerns, can be really helpful in increasing emotional intimacy.

All right. And now we move to the barriers to physical intimacy, which we know, as I shared, at some point, about 75% of folks with MS experience some barriers to physical intimacy. What's really important to note, too, is that barriers to physical intimacy is a common human condition across the lifespan as we age. And so there's definitely things that we can do to combat barriers to physical intimacy. So we understand barriers to physical intimacy in three ways. There are primary barriers. So these are from direct effects of MS. So these are the ways that demyelination impacts our sexual arousal or sexual functions. Then there are secondary effects, which are more about the indirect effects that are symptoms our medications might have on our desire to have sex or our ability to have sex. And then there are tertiary barriers to physical intimacy. And this is really about our feelings and attitudes, and again, our cultural messages. So the beliefs that we have about sex. Sex, as an act, is really an intersection of the mind and body. And some studies have suggested that up to 70% of the effect of sex, sexual arousal and climax is mental. And so sometimes our feelings and attitudes and cultural messages can get just as much in the way of our physical ability to have sex as some of our primary and secondary symptoms.

So in terms of primary barriers to physical intimacy, the libido or arousal, so having a decreased or absent interest in sex, it is a common barrier. Men can experience erectile dysfunction in the context of MS, women can experience vaginal lubrication difficulties, so that vaginal dryness, or engorgement that may cause pain. There can also be sensation changes, excuse me, so decreased sensation in our sexual organs or altered sensations that are not comfortable in the context of sex. And then sometimes orgasm or climax can be impacted so there can be a decreased intensity or frequency of orgasm or the ability to orgasm. And oftentimes the primary barriers can lead to some unintended outcomes, most commonly reported is sort of partners misinterpreting the loss of affection or interest, the loss of interest in sex or the loss of libido as a loss of interest in the relationship. So communication around the barriers to physical intimacy is really important.

There are also secondary barriers to physical intimacy. So fatigue, bladder and bowel syndromes and worrying about incontinence during sex, spasticity can make it hard to find a really comfortable position. Cognitive changes can make it hard to focus attention on maintaining arousal during sex, and then many of the medications that are prescribed can disrupt physical intimacy. So the meds for bladder can cause vaginal dryness, meds for spasticity can increase fatigue sometimes, and oftentimes meds like antidepressants can interfere with arousal and climax.

And then finally, those tertiary barriers to physical intimacy. So those beliefs can be about ability. So, you know, feeling like you're not attractive to yourself or feeling like other folks wouldn't be attracted to you. There can be negative beliefs about potential. So feeling like this will never change. There's no hope to fix this. And there can be negative beliefs about your partner. So my partner won't want to work through this with me, or my partner is not going to understand this. And all of those can disrupt physical, your physical intimacy.

So how do we combat physical barriers to intimacy? There are a number of ways. So for those primary effects of MS, for men, Viagra, injection therapies, penis pumps, there's a technique called body mapping where you move through your body with the therapist to identify where sensations are comfortable, where sensations are enjoyable, and where they’re not, and then also trying new positions can be really important. For women, some of those same strategies for primary effects of MS can be important. So using lubricant, body mapping can be a great strategy for women. For women, using toys and vibrators to help increase arousal and increase intensity of orgasm can help. And then meds to treat pain if there's vaginal engorgement can also be important.

Some of those secondary symptoms can be treated with strategy, what we call strategy, compensation strategy. So, for instance, planning a date or time for sex, if there's incontinence concerns, time toileting before sex to decrease the worry around having an incontinence issue during sex. Changes in diet can often help with some of those secondary symptoms. Stretching can help with spasticity to find more comfortable positions. For women, kegals can also be very effective. So there are a number of ways we can combat some of these physical barriers. And then for the tertiary beliefs and attitudes and cultural messages, really getting education, counseling and support to attempt to change some of those negative attitudes can be really, really beneficial. The key here is that there are a lot of strategies and there are a lot of options, and sometimes it takes a little bit of work to find exactly what works for you. But there's a lot of hope around increasing physical intimacy.

And now we're going to move to our last section, which is around navigating intimacy and commitment barriers. And commitment barriers to intimacy are those interpersonal barriers. So they exist in the way we engage friends and loved ones and caregivers. The commitment barriers are about doing the things to increase intimacy in our relationships. So combating those cultural barriers, combating some of those contextual barriers in our intellectual, emotional and physical intimacy. And commitment barriers are really rooted in the difficulty to change. Change is hard. Sometimes there's a fear of engaging differently. How do we do that? What does it look like? Sometimes it's hard to just understand how our relational engagement is blocking intimacy in the first place. Hopefully this talk has helped a little bit with that. And then sometimes there's difficulty in identifying the lines between unhealthy and healthy and culturally adaptive aspects of intimacy and love. So we don't just want to throw away the things we've been taught or how our culture shows up, but we want to engage culture in an adaptive and healthy way. So when we learn about and understand and confront both our cultural and contextual barriers, it can be an effective means of combating some of our commitment barriers to change.

So what we're going to talk about now is the dimensional model of relational intimacy and how we sort of think about contextual barriers. And so again, we can engage with each other in a healthy way, in an unhealthy way, and in a culturally adaptive way. I'm going to talk about the midpoints of this. So those culturally adaptive unhealthy are any cultural behaviors that result in disconnection, detachment, isolation or disinterest in our relationships. Black communities are a connected, interconnected community. Any time we're detaching, it's not very healthy for us.

Now, there are some types of engagement that can be healthy or unhealthy depending on the context. So for instance, in affectionate love, maybe you don't want to discuss an exacerbation or relapse with a friend. Well, if you're not discussing it because you really want to stay positive and it helps you sort of center yourself on sort of the positive aspects of how you imagine the exacerbation, moving through the exacerbation, then that could be a really healthy way to engage, especially if you're able to share your experience later. But if you're not sharing about the exacerbation because you don't want to be vulnerable or you don't want to appear weak, then that might be an unhealthy way of engagement.

For romantic love, let's say a decreased libido or interest in sex leads you to tell your partner you don't want to have sex. Well, that can be done in a really healthy way where communication around sex and your feeling and your desire can really help to aid in physical intimacy. But in unhealthy ways, if sort of you're telling your partner you don't want to have sex but you're not really interested in talking through why that is or helping to communicate around what may some actions be to sort of help you feel good about where you are, then that might be an unhealthy type of communication.

And then in self-love, maybe you tell yourself, I'm not worried about how I am about this. This is not, you know, sexual, emotional, affectionate relationship is not, it's not a big deal right now. If that's rooted in truth for you, if that's rooted in a self-acceptance, then that can be a really healthy thing. If it's rooted in sort of an avoidance of things that might be bothering you, then that's not self love. And sometimes we have trouble knowing the difference between self-protection, you know, I'm telling myself this thing that I don't care about it because I want to protect my heart from hurting. And self-love, we really want to move into self-love.

And then where I love for folks to be is in the healthy and culturally adaptive range of engagement. So this is where we engage our culture in really healthy and adaptive ways. So for instance, in affectionate love, maybe you establish small, you know, ongoing support needs with your friends that honor your relationship and, you know, you have, for instance, you set up something to have coffee once a month after your friend takes you to a doctor's appointment. So it's a way to, you know, both ask for support, but in the context of the friendship so that you're not feeling overly vulnerable.

Maybe in romantic love you develop a signal or communication with your partner when it's not a good day to have sex. So there's a way for you to communicate about what's going on for you with your partner that doesn't require you to actually talk about sex, if that's something that sort of is uncomfortable, culturally, still, or you're still learning the techniques about doing that. And then self-love, something that's healthy and culturally adaptive might be establishing a rest practice after any accomplishment. So, you know, you do something, no matter how big or how small, you clean the dishes or, you know, you write down something in your calendar that you said you would write down, and you get to have some sort of rest practice, whether that be a nap or, you know, reading a book or relaxing. You take care of yourself to give yourself sort of a loving embrace for doing those things. And these can be healthy and culturally adaptive, as you sort of combat the Superwoman/Superman complex.

All right. I'm actually going to skip this and I want us to have time for discussion. And so I'm going to go ahead and move us into the question portion. And I am looking forward to answer your questions and also hearing your thoughts. I saw the chat was was blowing up.

Marie LeGrand:

Wonderful. Thank you so much, Dr. Hunter. This was absolutely amazing. I really enjoyed, you know, hearing your presentation. And I think it's a presentation that can apply to so many individuals, whether you're living with MS, whether you're not living with MS, and regardless of your background and who you are, because you brought up so many important and valid points that many individuals can also relate to. So thank you. Yes. So we had some questions that came in earlier and we wanted to give everyone the opportunity to also put in their questions into the chat box. So just as a reminder, please be sure to type your questions. And we had a few come in, as I mentioned, prior to tonight's webinar, and we'll go ahead and start with this one: “How do you manage intimacy when treating one symptom can lead to another problem in intimacy in another way?”

Dr. Evelyn A. Hunter:

Yes, this is a really good question. And, you know, as I shared in the presentation, intimacy is really connected. And so oftentimes, you know, we start a new medication to address depression, and that creates, you know, some difficulties in arousal, for instance. I think really looking at this as a journey toward wellness is really important. And so increasing intimacy is a journey toward wellness. And oftentimes we have to find what fits best in that journey toward wellness. And so you don't want to think about increasing intimacy as a one time thing. It's something that we move toward across our lifespan, that we'll have different areas where we are really strong in specific parts of intimacy, in different areas, and times when we struggle. And so if you, for instance, start a new medication or you have a new symptom, that decreases an aspect of intimacy that you previously were working on or previously didn't have issue with, I think getting with your care partners, getting with your neurologist, your therapist, your romantic partners, your friends, and really crafting a strategy around moving toward wellness, and being patient in that journey, I think, is really important.

Marie LeGrand:

Wonderful. Thank you for that. Now, how do you talk with your partner about going to therapy or support groups to improve intimacy?

Dr. Evelyn A. Hunter:

That is a really great suggestion. I think it's really important in the context of black communities as well, because we often don't think about mental health as something that, you know, when I was growing up, my mom was like, black people don't go to therapy. Right? So sometimes we're trying to figure out how to talk to our partners and also combating some of those cultural barriers to getting help.

One way can be to really talk about the mutual benefit that sort of getting support can bring. And so in a partnership, you know, oftentimes the other person is feeling something, even if they're not sort of the primary person struggling. Right? So we oftentimes, in connection with one another, understand that there's something going on. And so, talking about the mutual benefit of bringing support into the partnership space can be really important.

The other thing is to take small steps. So sometimes it's easier for one person to seek therapy than the other. It's okay to seek your individual sort of self love and seek support for self first if your partner is not ready. Talking about that experience and being vulnerable about how this therapy support has been helpful can also help to open up our loved ones to the experience.

Marie LeGrand:
Wonderful. Now we had a couple of questions come in the chat box and I wanted to jump down to that. Is it abnormal that I wasn't taught any of the social barriers?

Dr. Evelyn A. Hunter:
No, this is not abnormal at all. I think that we often don't talk about intimacy enough, we don't talk about intimacy in our families, in our home lives. We don't talk about intimacy even in school. And when we think about health and sex ed, it's very sort of concrete to physical sex, and it’s very clinical, oftentimes. And so it's not abnormal at all not to sort of understand some of these really unique pieces. And we all have our own stories. And so there are likely more cultural barriers and contextual barriers that I didn't cover tonight that you may be experiencing. And so an exploration process can be really helpful in sort of getting to the bottom of what is really important in your life.

Marie LeGrand:
Okay, now how should I communicate with my partner when I can't meet his expectation?

Dr. Evelyn A. Hunter:
That's a good question. That can be a really difficult one. I think the first thing is to help to come together to identify what that word expectation means in the context of the partnership. So oftentimes expectation is not clear, but we kind of get feedback about when something's not going right. So we're not quite sure what we're supposed to do, and our partner is not quite sure why, you know, it's not clear what the expectation is.

So sometimes having those explicit conversations about what's not happening, what do you expect to be happening? And then where are the barriers to that? You know, fatigue is a real symptom with multiple sclerosis. Oftentimes you don't know when you wake up in the morning what type of day it will be. And so once we communicate around what those expectations are around sex, for instance, we might also be able to develop communication strategies about what's it mean, you know, if my partner wants to have sex at least three times a week, what does it mean if I have a week where I'm fatigued? And then how, what does my partner need for me to say around that? And what do I need for them to feel supported in that context? So that's a start, is really getting down to what those expectations actually are.

Marie LeGrand:

Okay. Now there was another question almost similar to that in terms of can you share ways in which to discuss intimacy challenges with a spouse or a partner? And you may have touched on that.

Dr. Evelyn A. Hunter:
Yeah. So the more concrete and explicit we can be, the clearer the communication, and we often learn to communicate without concrete language. Right? So we learn to say, “I'm not in the mood” when what we mean is “I don't feel aroused and I'm afraid that it will be painful if we have sex because I'm not getting lubricated.” Right? So those two types of communication are really different. “I'm not in the mood” allows for a lot of imagination. What might that mean? You don't like me anymore. I'm not sexually attracted to you. Here's this really physiologic thing that's going on with me is a very specific thing, right? There's not a lot of room for interpretation. So one of the strategies that I talked about was writing things down. That can be really helpful, especially because many of us are uncomfortable talking about sex, that can be helpful to really help us clarify what it is we want to communicate around sex, emotional intimacy, even affectionate intimacy. You know, it can help us to sort of clarify what are the things that I need to say here so that we can wrestle with the language to say them and really get a clear message across.

Marie LeGrand:
Wonderful. I'm going to try to get, because I know we’re, you know, unbelievably running out of time, and we have so many amazing questions. And as always, I wish we had more time for these programs. But one of the audience members asked: “As a woman, what are some meds to treat pain?” I'm not sure if you, you know, that's something you can perhaps touch on.

Dr. Evelyn A. Hunter:
Yeah, this is a good question, but also out of my wheelhouse as a psychologist. What I would strongly encourage is to have... so we talk about in MS, all the time, having a care partner treatment team. Right? So that includes your neurologist, as a woman that might include an OB who has an understanding of multiple sclerosis or at least autoimmune condition. A therapist on that care partner team. And then, also, oftentimes a nutritionist and physical therapist can be really helpful around pelvic pain. There's sometimes some physical therapy that you can do for vaginal pain in addition to medication. So I would start there in getting a team together. So to help you think about what might be an important medication and how it might interact with other aspects of MS and what things you can do along with MS.

I saw that “what's a good lubricant?” come in the chat - water based is all you need to know. As long as there's water based, you should be good to go.

Marie LeGrand:
Okay. Okay, so there is a question around MS and menopause: “So I have MS and menopause. My sex drive is on zero. Is there anything I can do to bring my body back to life? Please advise on how to,” and this is kind of a part two, “please also advise on how to change my mindset to feeling desirable or sexy.”

Dr. Evelyn A. Hunter:
Yes, this is a good question. So absolutely you can bring your body back to life. And many do it post menopause or in menopause. There are a number of hormone therapies. Again, you get with your care partner team to discuss the interactions with MS in that context. The other thing that I will say is that oftentimes we forget about the times that we do feel sexy or desirable. And

so if you can think back to when that happened, when that was for you, what was going on? Was there a certain look? Did your hair do a certain way? Was there certain clothes that you wore? What about those times might you recreate in your current context? Those are things that you can do to help sort of trick your mind into remembering the way you felt when you felt desirable, so that recreation can be a strategy that you might use to navigate some of that mental aspect.

The other thing that you might do is to engage in some sexual fantasy, which can be a really healthy way to sort of get your mind reconnected with your body. And so there are really good therapists that can be helpful in sort of helping through strategies, but those are some quick ones that I would say. Do things that make you feel good, that you remember that you did when you remember feeling great about yourself.

Marie LeGrand:

Wonderful. And then this will be the last question before we close: “For singles with MS, are there recommendations on how to approach dating?” And another individual asks, you know, almost aligned with that question: “Are there any websites that you can recommend to meet people living with MS?”

Dr. Evelyn A. Hunter:

That's a really good question. I actually don't know of websites specific for meeting people living with MS, but that's a great idea. And you should start that whoever asked that question. There are a couple of things that I would say. One is that, in the context of dating, I know it can be hard, but I want you to imagine what you want at the end of the road. So what's your goal for dating? And imagine what that relationship should look like. So I think oftentimes folks immediately sort of bring themselves all the way in and minimize all the things that might be important for them in a relationship that they desire because they want to have more access to dating at the beginning. But that can often get you in that catch 22 that we talked about, where it's hard to connect with anybody because you're not really being yourself, you're not being authentic, you're not sharing the things that are really important to you about life.

But remember that the right partner is going to be able to navigate those things that are really important to you. And so I would spend some time really reflecting on what do you want the end to look like? What's important for the person to know about you in the context that you live, in the context of your MS? What types of intimacy are important to you? What does that look like for you? And sort of use that as sort of a guide at the forefront of the dating relationship. And I see somebody put in the chat that BelongMS has a section. So thank you for that.

Marie LeGrand:

Yes, wonderful. Well, thank you so very much, Dr. Hunter. You know, the time is already up. It went by so fast and you've provided us with just a lot of tools, a lot of amazing, wonderful information that, you know, many of us can take with us as we are developing these relationships and building intimacy within our lives. So again, this has been such an amazing and insightful program. So thank you once again.

This concludes the webcast. Tonight's webinar was recorded and will be made available on our website. Please do visit MSAA's calendar of events for our upcoming webinars and events. And on behalf of MSAA, we would like to thank you once again, Dr. Hunter, for taking the time and providing us, as I mentioned, with the tools needed to better understand intimacy while living with MS, as well as one's relationship with theirselves and others.

To our wonderful audience, we would like to thank you for joining us this evening. Please take a few minutes to complete the brief survey, which will appear on your screen momentarily and know that we are thinking of the entire MS community and hope that you and your families continue to stay safe. Thank you and have a good evening.