

Carrie's TOUCH: Supporting Black Women with Breast Cancer



Editor's Note: In this edition of *Oncology Issues*, 2021-2022 Association of Community Cancer Centers President Krista Nelson, MSW, LCSW, OSW-C, FAOSW, announced her President's Theme: "Real-World Lessons from COVID-19: Driving Oncology Care Forward." One of the key lessons learned is that health equity and social justice are critical drivers of quality cancer care delivery. Although cancer incidence and mortality overall are declining in the United States, certain underserved patient populations continue to be disproportionately impacted by certain cancers. To help ensure equitable access and quality cancer care for *all* patients—regardless of race, ethnicity, age, gender identity, income level, sexual orientation, and/or geographic region—the Association of Community Cancer Centers is shining a spotlight on pioneering organizations and individuals, like Reverend Tammie Denyse, who are moving the needle on health equity.

Tammie's Story

Tammie Denyse, MDiv, MCL, co-founder and president of Carrie's TOUCH, was diagnosed with stage 2B invasive ductal carcinoma breast cancer 16 years ago. At the time, she was 39 years old and a single mother of three children. "When I was diagnosed, I knew there was going to be something different about my journey," Rev. Tammie explains. "That there was going to be a greater intention with the work I would do following my diagnosis."

Accompanied by her support system, which included six of her closest friends, Rev. Tammie met her oncologist, who shared with her a clinical trial opportunity that could potentially save her life. He said to Tammie, "This trial is perfect for you."

Even though this was Rev. Tammie's first experience with cancer and cancer research, she knew to ask one key question:

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Tammie Denyse, M. Div., MCL. Photo courtesy of April Taylor.

How are Black women responding to this new treatment? Her oncologist did not know. “That just stunned me,” she says. “I literally said unacceptable—it is unacceptable for you [my oncologist] to come into this office and present a treatment we are looking at that could save my life, and you don’t

know how women who look like me are responding.”

This inspired a dynamic patient-doctor relationship between Rev. Tammie and her oncologist. She was determined to participate as much as she could in her treatment decisions. After she was sent home with a 32-page document of information about the trial and possible side effects, Rev. Tammie requested a meeting with the identified clinical trial’s head researcher. Carrying with her a laundry list of questions, she met with the researcher for more than four hours. With all of the information she received, still no one could tell Rev. Tammie how Black women were reacting to the treatment being studied in the trial.

“Needless to say, the decision I made wasn’t a decision for me,” Rev. Tammie explains. “I said to myself: if I enter this trial, at least they will have information on one Black patient.”

Her response to the treatment was one of the worst cases her oncologist had seen in his 20 years of practice. After she began participating in the clinical trial, Rev. Tammie’s support system, which she affectionally calls, her “Tribe,” became concerned for her quality of life due to the serious side effects she was experiencing. “I just refused to stop the trial because I knew it was going to serve a greater purpose at some point,” she says. “Every decision I made wasn’t necessarily a decision for my own personal journey or my own personal comfort, but it really was a decision made with others in mind. I was bold enough to believe that my

journey with breast cancer could actually affect future advancements in medicine. Navigating the murky waters of a breast cancer journey is complex. Therefore, it is my greatest desire that people will look at my life, my experiences, and my journey to find hope.”

Carrie’s TOUCH

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“As I was fighting to figure out next steps with my own healing process, I wanted and needed a support group with women who understood my perspective as a Black woman. Disturbingly and sadly, there were none in my area,” Rev. Tammie explains. “My oncologist was concerned about my survivorship. My cancer was aggressive and had already spread, and he wasn’t confident I would make it to the coveted five-year anniversary disease free.”

With this news, she began searching the Internet for any information on breast cancer, Black women, and survival. Rev. Tammie found only one study, from the American Cancer Society, that shared information on Black women with breast cancer. Yet the findings of the study did not offer much hope. Instead, it only perpetuated the narrative of the disproportionately high mortality rates for Black women. “I was appalled and became determined to make a difference, effective immediately. I needed to create a space curated by Black women for Black women battling breast cancer,” she says.

Thus, Carrie’s TOUCH was born. Along with 12 women who wanted to be part of the change, the work began to communicate a message of hope, inspiration, and survival to better support Black women with breast cancer. “We understood the importance of creating a culturally sensitive and safe space: a space that felt familiar, where women felt comfortable being vulnerable enough to share their most intimate stories about breast cancer, and a space where sharing expanded beyond conversation to removing uncomfortable wigs and/or prosthesis at times,” Rev. Tammie explains.

Carrie’s TOUCH dedicated its mission to breaking the silence that adversely impacts Black women with breast cancer. “The statistics of Black women still dying, 16 years later, at an approximately 41 percent higher rate than our Caucasian sisters is exasperating. It’s long overdue for that number to change. It’s time to close the gap,” she says. “This organization began as a voice to fight for those who cannot, will not, or who do not know how to fight for themselves. We do that through our TOUCH: Teaching, Outreach, Understanding, Caring, and Healing. Our framework includes advocacy, awareness and education, research, and support.”

Supporting Black Women Everywhere

One of the most vital initiatives of Carrie’s TOUCH is educating Black women on breast cancer and what to do when diagnosed, which is often realized by meeting with patients before their oncology consultation and accompanying them as an advocate

to the consult. This is one of the ways the organization stays in touch with its patients.

“We meet women where they are. Pre-COVID we would go to places where other organizations wouldn’t. We’d go into their homes, their doctors’ offices, on their jobs, or wherever they needed us,” Rev. Tammie explains. “Our goal is to educate and empower women to know their rights as patients and to use their voice to be their own advocates.”

Carrie’s TOUCH helps women digest the news of their cancer diagnosis and prepare for their consultation so that in the limited time frame they have with their cancer care team patients leave informed and ready to participate in shared decision making. “We give these women new perspectives on how to look at their diagnosis. Instead of asking, ‘Am I going to die?’ consider asking, ‘What treatment options are available to help me live?’” Rev. Tammie adds.

COVID-19 has greatly impacted the organization’s ability to meet patients where they are, as the in-person touch that Rev. Tammie and her team take pride in has been put on hold to keep patients safe. “We always want to give that human interaction as a personal touch,” Rev. Tammie says. “We’ve had to reimagine what that looks like in this climate. With COVID-19, that just does not happen because our women are immuno-compromised. Now, we rely more on that face-to-face and one-on-one we have with patients over Zoom. We’ve reinvented how we conduct our support groups, too. We now have multiple online opportunities for survivors to connect.”

Though COVID-19 has impacted the organization’s ability to work in person with women, Carrie’s TOUCH uses its voice on social media to continue its mission. The social media campaign #BreastCancerBeLike was released Oct. 15, 2020. Part one of the three-part video series portrays two women—one White and one Black—who receive a breast cancer diagnosis and the traditional doctors’ visits and support these women receive. With the same breast cancer diagnosis, Carrie’s TOUCH shows that White women are often flooded with support from their cancer care team and by other breast cancer organizations, whereas Black women and their needs are ignored, and they are often left alone to understand and navigate next steps. This video highlights the unfortunate truth that Rev. Tammie has seen Black women experience time and time again, including the lack of support she received from her own doctor upon delivering her diagnosis of breast cancer. The second video in the series helps women by highlighting common terms and experiences patients face, while also putting Black women in the spotlight so viewers can see themselves and their stories told. Using humor as a teaching tool, Carrie’s TOUCH highlights the reality Black women face during their cancer treatment journey. These videos educate the general public and they help build a sense of community for Black women who may feel ignored and alone by showing women that others face the same struggles and needs.

“#BreastCancerBeLike continues to advance the necessary conversation on Black women with breast cancer by illuminating the racial injustices and inequalities,” says Rev. Tammie.


Cancer Research

Because of Rev. Tammie’s experience with a clinical trial, she wanted to include cancer research as an important component of Carrie’s TOUCH. In partnership with the University of California Los Angeles, Carrie’s TOUCH initiated Project SOAR: Speaking Our African American Realities.

“We began this project almost four years ago when there was nothing in the literature that looked at the Strong Black Woman concept and its impact on Black women diagnosed with breast cancer,” explains Rev. Tammie. “Our goal with Project SOAR is to literally break the silence. We are listening to the unique stories of Black women with breast cancer. Stories some women have only shared with us. Their stories matter. Their stories deserve to not only be heard but their stories need to be considered when developing oncology pathways. We want the patient voice in the driver’s seat of shared decision-making. It was lifesaving for me to know I was making informed decisions with my oncologist and medical team, about my life.”

Project SOAR gave Black women diagnosed with breast cancer the opportunity to share their story and the experience of their cancer journey. Project SOAR has since finished data collection for Phase II and reached its minimum goal of participants. Data is now being analyzed in preparation for documenting Project SOAR findings.

“As we were in the final days of recruitment for Phase II of Project SOAR, we looked to the future of developing ethnocentric, patient-centered care pathways,” explains Rev. Tammie. Carrie’s TOUCH is unpacking what the pathway is that would adequately accommodate a Black woman while she is on her breast cancer journey, leaving her whole instead of fragmented on the other side. “We’re considering the whole woman—mind, body, and soul before, during, and after treatment. We are acknowledging the complexities of the new normal these women face. As she reinvents herself, we want the woman to embrace her mental, physical, emotional, spiritual, and financial well-being,” says Rev. Tammie.

The political and social justice issues and conversations sparked again in 2020 around the experiences of the Black community in the United States were not new to Rev. Tammie and her team. She experienced the racial disparities and insensitivity that exists in the U.S. healthcare system firsthand and has since dedicated her work to changing that narrative through Carrie’s TOUCH. As Carrie’s TOUCH dedicates its mission to improving the lives of Black women everywhere who may feel isolated and unsupported upon receipt of a breast cancer diagnosis, Rev. Tammie wants all Black women with breast cancer to know one thing: “Black women can and do survive breast cancer.” 

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