CANCER SUPPORT
COMMUNITY
SAN FRANCISCO
BAY AREA


“People who were like me needed support.”

Addressing Health Equity in Supportive Cancer Care for Black Cancer Patients and their Families

From the CSC Board President

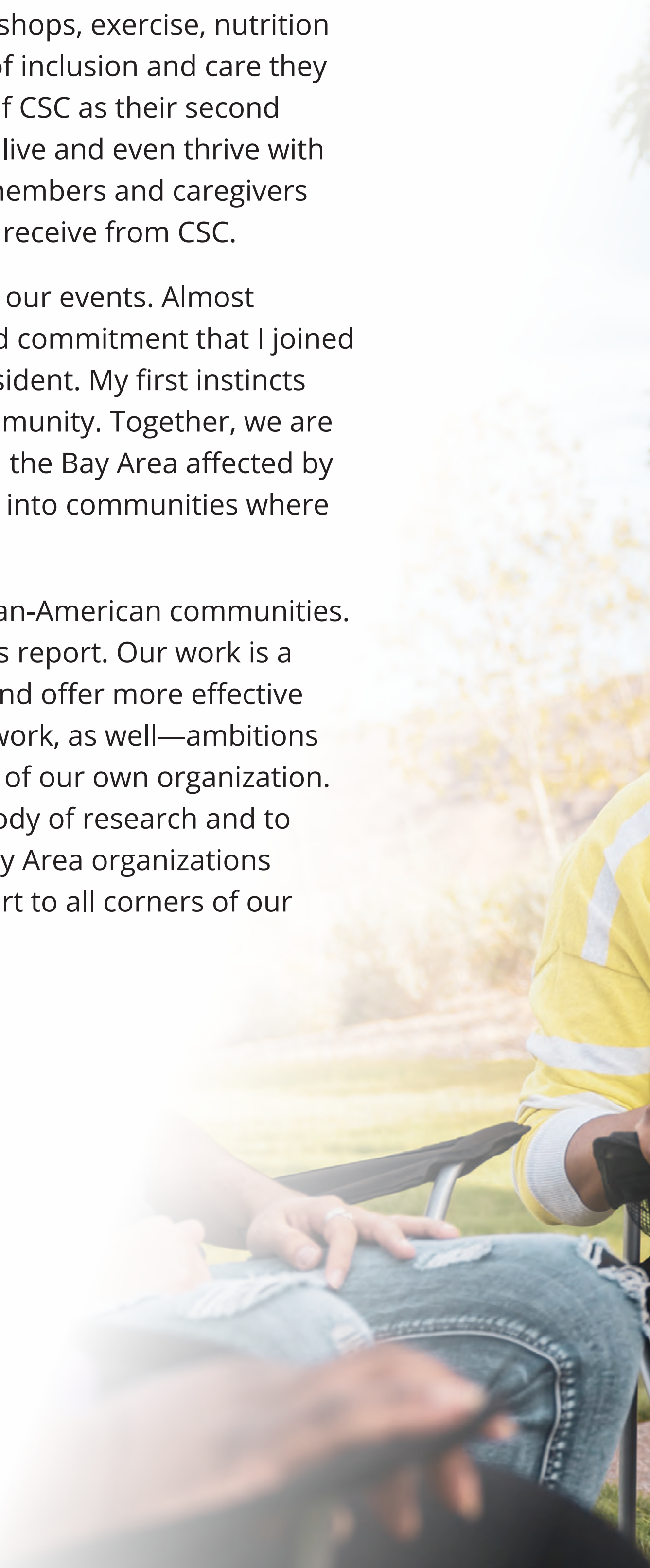
Spend just a few minutes with a cancer patient who has participated in Cancer Support Community's (CSC) programs, and you'll be struck by how profoundly they feel connected to the organization and their fellow community members. For some it is the support groups, educational workshops, exercise, nutrition or creative arts classes. For others it is the feelings of inclusion and care they experience in our community. Many of them think of CSC as their second home—a safe, caring and inclusive place to learn to live and even thrive with their cancer diagnosis. The same is true for family members and caregivers who feel more capable because of the support they receive from CSC.

I first experienced CSC when I participated in one of our events. Almost immediately, I felt such a strong sense of impact and commitment that I joined the board. Today I'm honored to be the board's President. My first instincts were right. This is an amazing organization and community. Together, we are on a purposeful journey toward helping everyone in the Bay Area affected by cancer, with a special focus on bringing our services into communities where such services have been mostly unavailable.

Cancer has a disproportionate impact in Black/African-American communities. That's why our Board is committed to publishing this report. Our work is a first step for CSC to ensure greater understanding and offer more effective programming. We have broader ambitions for this work, as well—ambitions that extend beyond the boundaries and capabilities of our own organization. We are hoping to add new insights to the existing body of research and to build enthusiasm and commitment among other Bay Area organizations so together we might all work to bring critical support to all corners of our communities impacted by cancer.

Donald

Donald Duggan
President, Board of Directors



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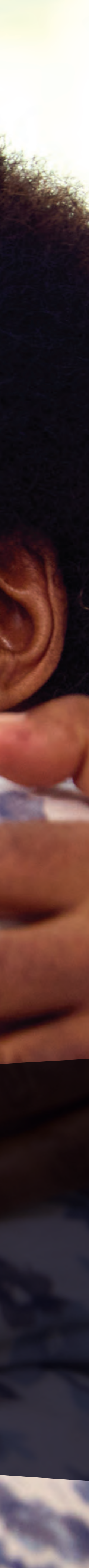
>
> ▪ **Donald Duggan**
> CSC Board of Directors President

> “Once you get diagnosed, there’s a lot of fear, there’s a lot of concern, there’s a lot of realizing you don’t have a lot of information... Cancer Support Community has been really great for me and my family. I urge anyone that has any kind of concern regarding their cancer treatment to reach out to the Cancer Support Community for help.”
>
> ▪ **Al, CSC participant**



Introduction: Why this report?

Cancer does not discriminate, but not everyone with cancer is treated equally. For the 1.9 million people diagnosed with cancer every year in the US and the 18 million survivors, the consequences of health inequity are profound. Some of the many factors causing this inequity are a patient's race, ethnicity, income level, gender, age, language, sexual orientation, gender identification, educational level, and where they live. Because our goal is to improve outcomes and quality of life for cancer patients, we must find ways to address the inequities in care. Dr. Monica Bertagnolli, cancer survivor and Director of the National Cancer Institute, describes it best when she says, "In tackling a problem like cancer, we can't afford not to have full engagement across the spectrum of diversity that represents all of society."

For over 30 years, Cancer Support Community San Francisco Bay Area (CSC) has helped thousands of cancer patients and their families in the Bay Area through free support programs, educational workshops, counseling, and wellness activities. We are committed to addressing health inequities in cancer care, especially those related to psychosocial support. Research has shown that programs addressing social, educational, emotional, and financial needs can improve health outcomes and quality of life for both cancer patients and their family members. CSC's goal is to ensure that these programs are universally available to all cancer patients as part of standard care. Yet this is not true today; communities of color often lack these programs and suffer disproportionately worse outcomes when affected by cancer. This is especially true for Black/African-American cancer patients, who have higher levels of morbidity and higher mortality rates than other groups.

While CSC welcomes all cancer patients, survivors, family members, and caregivers who need our support, we are also looking for ways to better reach and serve under-resourced communities. As such, CSC's Board of Directors and staff are committed to making our services and programs more inclusive and engaging to more diverse communities. Thus, in early 2020, CSC opened a second support center in East Contra Costa County, a much more diverse community where statistics show that the impact of cancer is dramatically more dire for Black/African-American people, people of color, and people with lower incomes. CSC also added a staff position to focus on reaching communities experiencing the highest levels of inequity.

This report grew out of a desire by CSC to understand how we can better support the needs of Black/African-American cancer patients and their families, and it is an important first step toward that goal. We are publishing this report to add our insights to the conversation and improve how our organization and other health professionals serve cancer patients from under-resourced communities. We hope to keep the focus on health equity in cancer care as well as provide positive actions we can all take to address this issue.

How does cancer impact the Black/African-American community?

Cancer outcomes show stark disparities along racial and ethnic lines. Black/African-American cancer patients experience among the very worst outcomes. Although a recent study found that cancer incidence decreased slightly between 2013 and 2018 for all racial groups, Black/African-American people continue to have the highest incidence rates for prostate, colon, and rectal cancers as well as one of the highest rates for new breast cancers (Kaiser Family Foundation [KFF], 2022). Black/African-American cancer patients are more likely to be diagnosed at later stages, and they have the lowest overall survival rates of all ethnic/racial groups in the United States. Despite cancer mortality rates also decreasing for all groups, Black/African-American people continue to have the highest mortality rate for most leading cancer types including female breast cancer, prostate cancer, colon cancer, and rectal cancer (KFF, 2022).

Two key drivers of these disparities are structural racism and systemic discrimination. Practical barriers to accessing care also include a lack of reliable transportation, inadequate health insurance, and disruption in employment (ACS, 2022). Taken together, these stressors can lead to more dire cancer care outcomes.

What is the role of social determinants of health in cancer care?

According to the Centers for Disease Control, social determinants of health are “the nonmedical factors that influence health outcomes” and include “conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.” In the last few decades, a movement has grown in cancer care to treat the “whole person,” including providing psychosocial services. Psychosocial services are defined by the Institute of Medicine (IOMS) as “psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health.” In addition to medical treatment, providing appropriate psychosocial interventions according to the patient’s level of distress has proven to improve quality of life and has been associated with better cancer care outcomes. (Effective psychosocial interventions can address psychosocial burdens of cancer treatment. Pirl et al., 2014).

With this knowledge, CSC utilized a validated Distress Screen to understand the specific psychosocial needs of Black/African-American patients and their families. This report shares the results of this survey, correlates relevant research, and addresses the need for CSC’s services and programs.

What do the literature and the CSC survey tell us?

Because of the small sample size of the survey, this report also includes research from an extensive literature review.

Survey demographics and background information

The survey yielded a total of 25 responses – two thirds were patients or survivors (hereinafter referred to as patients) and one third were caregivers or family members (hereinafter referred to as caregivers). Of the cancer patients who responded to the survey, half were diagnosed with breast cancer, and half were in active treatment. There were more female identified respondents than male respondents (75% and 25% respectively), and most of the caregiver respondents were female identified. Among cancer patients, over half had some college, technical, vocational school, or graduate degrees. Of caregiver respondents, three quarters had graduate degrees. Just under half of the cancer patients were married, followed by a third who were not married. Approximately one third of the cancer patients were retired, one third were on disability, and just under 20% were employed full time. There were wide differences in income levels ranging from less than $20,000 to above $100,000 per year with most respondents between $60K to $100K.

The survey respondents reside in Alameda or Contra Costa County, with the majority in Alameda County.

California (394.7 per 100,000 residents) has

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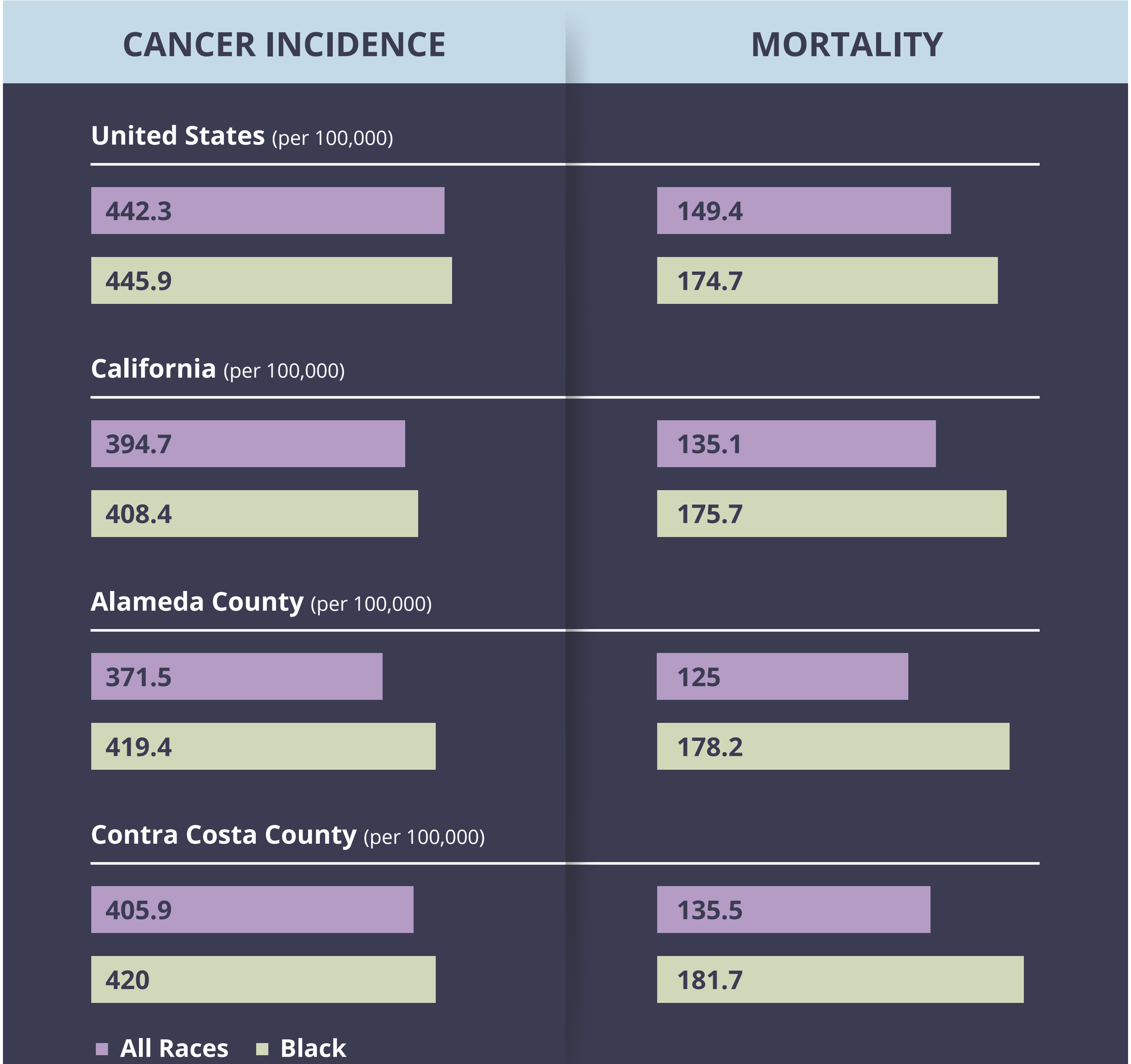
a significantly lower cancer incidence rate than the US overall (442.3). The story is more dire for Black/African-American people, however. In both Alameda and Contra Costa County, Black/African-American cancer incidence is much higher than California overall. Even though these counties are doing better than the US as a whole, the disparity of cancer incidence for Black/African-American people in these counties is significant.

The disparity is even more stark in cancer mortality. In California overall, the Black/African-American mortality rate (175.7 per 100,000) is 30% higher than for all races (135.1). It's even worse in the two counties covered by the survey: Contra Costa's mortality rate for Black/African-American cancer patients is 34% higher than for all races, and in Alameda County that goes up to 43%.



National Cancer Institute [NCI], statecancerprofiles.cancer.gov/

What themes emerged from the survey and literature review?

The impact of a cancer diagnosis goes far beyond the medical health of the patient. Both patients and caregivers have reported significant changes with employment due to cancer diagnosis and treatment. A study of 202 caregivers of cancer patients in Detroit, Michigan found that 74% of caregivers of Black/African-American cancer patients made some employment change. Of these, 60% changed their schedule, hours, duties, or employment status; 15% took at least 1 month off to provide care; and 38% reported difficulty balancing work and caregiving. Employment changes were strongly associated with difficulty balancing work and caregiving, as well as with increased financial burden. In addition, these factors are also associated with increased anxiety and depression (Hastert et al., 2020). In the study, 94% of the patients and 100% of the caregivers answered that there had been changes or disruptions in school, work, or home life after the diagnosis.

Existing literature suggests that Black/African-American cancer patients and caregivers often experience financial distress. Sánchez-Díaz et. al. (2021) found that Non-Hispanic Black/African-American and Hispanic patients were more likely to have unmet financial, emotional, and practical support needs than whites. Worries about money or health insurance were reported by 64% of the patients. In another study that examined the association between race and financial toxicity, Black/African-American people were more than five times as likely to be denied insurance and more than twice as likely to report being hurt financially because of cancer than white people (Panzone et al., 2022). Fenton et al. found that compared with non-Hispanic white caregivers of cancer patients, Black/African-American and Hispanic caregivers spent more time caregiving, completed more tasks, and reported greater financial burden (2022). Additionally, according to American Association for Cancer Research (AACR) Cancer Disparities Progress Report (2022), 68% of Black/African-Americans and 58% of Hispanics reported experiencing financial hardships one year after cancer diagnosis, compared to 45 percent of non-Hispanic whites. Also, both Black/African-American and Hispanic groups reported being negatively impacted financially twice as often as white individuals. In the CSC survey, 78% of caregivers answered that they were concerned about managing household finances and managing health insurance and medical bills, while 63% of patients answered that they were experiencing health insurance or money worries. This indicates that financial distress weighs heavily on the caregiver respondents.

Although there are few studies that specifically examine the prevalence of depression among

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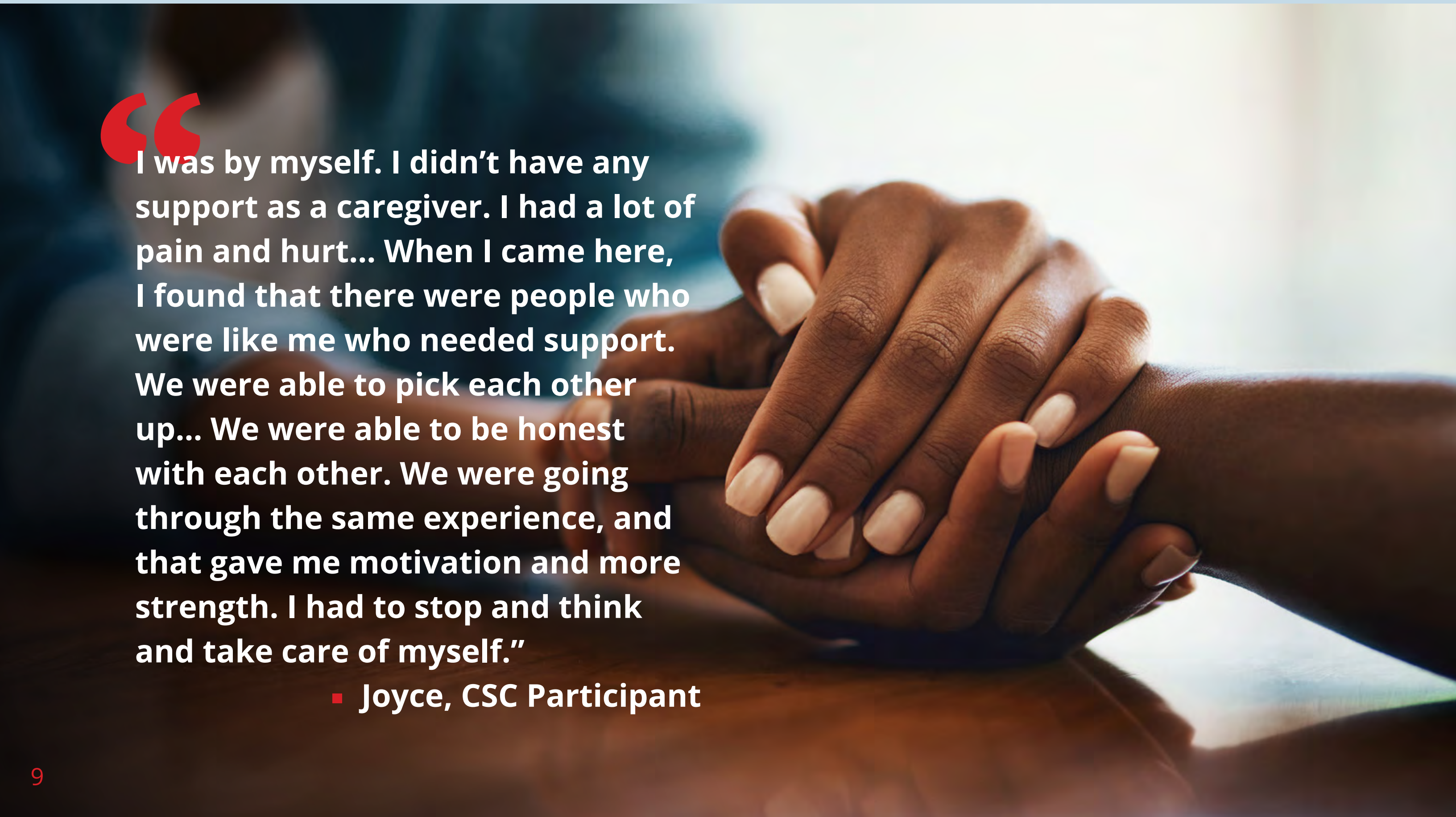
Black/African-American cancer patients, the studies that are available suggest that ranges of prevalence could vary from 12-27% (Kang et al., 2020). As previously noted, distress related to employment and financial burden has been associated with anxiety and depression. In the CSC survey, 75% of the patients said that they had felt sad or depressed to various degrees, and 81% answered that they had felt nervous or afraid. More than two-thirds (69%) of the patients also said they had felt lonely or isolated. In addition, 100% of the caregivers stated concern about their loved one's changes in mood and behavior. Importantly, all of the caregiver respondents expressed feeling sad or depressed as well as feeling lonely or isolated. These results indicate that psychosocial programs need to address emotional distress not only of the patients but also of the patient's family members and caregivers.

More than three-quarters of the patients in the CSC survey expressed these other areas of concern: pain and physical discomfort (88%), body image and appearance (87.5%), treatment decisions (75%), exercise and being physically active (87.5%), and thinking clearly (75%). More than half (63%) expressed concern over intimacy, sexual function or fertility. Tobacco or substance abuse did not appear to be a great concern among respondents (13%).

Caregiver respondents overwhelmingly expressed concern with changes in the patient's memory or thinking (100%), eating and nutrition (100%), treatment decisions (100%), and coordinating medical care for the patient (90%). Even with a small sample size, this consistency of experience signifies that caregivers take on many emotional and practical burdens that can cause stress and concern for both the patient and the caregiver.



> **"I was by myself. I didn't have any support as a caregiver. I had a lot of pain and hurt... When I came here, I found that there were people who were like me who needed support. We were able to pick each other up... We were able to be honest with each other. We were going through the same experience, and that gave me motivation and more strength. I had to stop and think and take care of myself."**
>
> ▪ **Joyce, CSC Participant**

What are barriers to accessing support programs?

While it's difficult to draw clear conclusions from the small sample size, the survey gives some indication where cancer support organizations may focus their efforts to increase utilization of psychosocial support programs.

Some indicators of low participation included "it is difficult to find time" (20%) and "not enough information is available" (20%), and most importantly that "I might feel uncomfortable or out of place" (27%). This may indicate a need to improve the cultural relevancy and clarity of outreach materials and tactics as well as ensuring that programs feel welcoming and inclusive. Such improvements may include utilizing Black/African-American facilitators and instructors for program delivery as well as more culturally competent marketing efforts to raise awareness of the existence, content, safety, and efficacy of support programs.

Caregivers expressed different barriers to participation. Half of caregiver respondents selected "it's difficult to find the time," and 38% of respondents selected "lack of transport/I can't easily get to it." Feeling uncomfortable or out of place was also a significant concern (38%). This may indicate that caregivers' concerns are more logistical in nature, with the burdens of caregiving causing stress over money, time, and personal capacity. With such concerns in mind, increasing caregiver participation in psychosocial support programs may be served by focusing on providing logistical support (e.g., rideshare gift cards) as well as enhanced programming for caregivers to help build competencies in personal time and resource management. This result is supported by a needs assessment done by Drexel University researchers that included 72% of Black/African-American cancer patients with more than 90% of the all respondents being parents of school aged children (Davey et al., 2016). In this needs assessment, parents with potential interest in psychosocial support programs reported that they would need assistance with transportation, parking, babysitting for younger children, convenient times/places, and refreshments. Regarding the time constraints, it is important to assess when would be the best time for patient and caregivers respectively, which may be outside regular office hours.

What are the most desired services?

Patients and caregivers were both asked about the programs they wanted, as well as the programs they were most likely to participate in. The results reveal differing needs: patients tend to want education and activities designed for healing, while family caregivers gravitate toward communal support and education.

Patients indicated that the support programs that would best help them cope with their cancer diagnosis were:

- Educational workshops on cancer-related topics (63%)
- Exercise (50%)
- Writing, art, and music classes (44%)
- Information about available resources (44%)

This stayed relatively consistent when patients were asked how likely they were to participate in different kinds of programs, with some slight reprioritization:

- Exercise (69%)
- Educational workshops on cancer-related topics (56%)
- Writing, art, and music classes (50%)
- Information about available resources (50%)

These numbers suggest a strong need and desire for psychosocial programs to help with healing and wellness such as exercise, creative arts, and focused education.

Caregivers, on the other hand, appear more focused on the practical aspects of living with cancer. These results echo the barriers to participation that caregivers noted in previous questions.

Caregivers said the programs that would best meet their needs were:

- Support groups (56%)
- Educational workshops on cancer-related topics (44%)
- Information about available resources (33%)
- Emergency and financial help (33%)

When asked what programs they would participate in, however, caregivers also included wellness and healing-oriented programs along with the practical:

- Support Groups (68%)
- Exercise (56%)
- Educational workshops on cancer-related topics (33%)
- Writing, art, and music classes (33%)
- Groups for parents whose children have cancer (33%)
- Emergency and financial help (33%)

What can we learn from this report?

This new survey, combined with other existing research, can provide guidance for program design, program delivery, and improved outreach to communities of color and under-resourced communities. With this in mind, and drawing on CSC's 30-year history of providing highly effective and beloved psychosocial programming, below are several suggestions for consideration.

- Hire and train peer facilitators and counselors that identify as Black/African-American who share similar lived experiences and background as the intended participants. Past studies have consistently shown that Black/African-American cancer patients and caregivers have strong preferences for peer support (Haynes-Maslow, Allicock & Johnson, 2017; Gordon et al., 2022). This report proposes incorporating a peer-support model targeted to Black/African-American cancer patients and caregivers in which group facilitators are recruited from the Black/African-American cancer community and trained as facilitators instead of relying on licensed clinicians on staff who do not identify as Black/African-American. Integrated literature review of psychosocial interventions for African American Breast Cancer Survivors (AABCS) revealed that the lack of representation of AABCS experience both during and after treatment can contribute to feelings of isolation; therefore, it is vital that psychosocial interventions encourage social support between fellow AABCS (Gordon et al., 2022). Garza et al. found in a qualitative study of 30 African American Breast Cancer survivors in the Midwest that African American

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women resist oppression through cultural support and advocacy (2022). These studies highlight the need for representation among those who facilitate groups and activities at CSC. The national chapter of Cancer Support Community has already begun the Peer Clinical Trial Support Program, which matches Black/African-American cancer patients with a peer specialist who has participated in a clinical trial, and who can provide tailored support and consultation (Cancer Support Community [CSC], 2023). This could serve as a model for other CSC affiliates and community-based organizations to follow in incorporating peer support into their resources.

- Join forces with other CSC affiliates and community-based organizations to co-host Black/African-American cancer patient and caregiver support groups. It may prove beneficial to forge efforts with other affiliates within the state of California to provide support groups and educational programs that are specifically tailored to the needs of Black/African-American cancer patients as well as caregivers. This may allow for joint training programs to train group facilitators including non-licensed clinicians (MSW, AMFT, and peer group facilitators) to better utilize available resources and reach more participants in larger geographic areas.

- Provide practical and logistical support such as gas/bus/rideshare cards, financial assistance, and patient navigation. As evidenced by the literature and survey results, providing practical support such as transportation and financial assistance can mitigate the barriers to accessing services, particularly for Black/African-American caregivers. In addition, providing other forms of practical support such as emergency financial assistance and patient navigation should also be considered, as these types of support would have a direct and immediate impact on easing psychosocial burdens of Black/African-American patients as well as caregivers.

- Offer educational workshops and psychoeducation focused groups that are tailored to addressing specific needs of Black/African-American patients hosted by Black/African-American educators, providers, and clinicians.

- Partner with organizations that can offer expertise in health insurance, employment and legal issues, and financial planning that can address broader social determinants of health to supplement psychosocial support services already offered at CSC.

- Build coalitions and establish community partnerships. Solutions to reducing cancer care disparities need to be addressed on a community and macro level with partners across multiple sectors. A good example of this is Greensboro Health Disparities Collaborative (GHDC), a partnership consisting of community leaders, advocates, public health researchers, academic faculty, clergy, and other community members. This coalition has resulted in a National Institutes of Health (NIH) funded intervention successfully closing the gap of cancer care for Black/African-American and white lung cancer patients (Cycert, et al., 2018; The Greensboro Health Disparities Collaborative [GHDC], n.d.). This illustrates how broad and community-based collaborative partnerships can address systemic inequities, which could be applied to developing more accessible and equitable psychosocial programs for Black/African-American cancer patients and caregivers.

What are the limitations of this report?

Capturing the needs of Adolescent and Young Adult (AYA) patients

Adolescent and Young Adult patients are commonly described as those who are living with cancer between ages of 15 and 39 (ACS, NCI, 2023). As most of the studies tend to include older cancer patients and survivors, the specific needs of AYA Black/African-American patients and survivors may not have been captured. Specific focus groups or surveys targeted to AYA patients may be helpful in identifying the needs and preferences of this specific population.

Lack of literature assessing the effectiveness of virtual programs specifically targeted to Black/African-American patients and their caregivers

While most cancer support programming quickly transitioned to virtual formats during the pandemic, there is a scarcity of studies evaluating the effectiveness of virtual support programs for Black/African-American people living with cancer. Such studies will take some time to be published. Virtual support programs could be a way to offer more equitable services because of the ease of being able to participate from anywhere; careful examination is needed, however, in order to ensure that it is in fact meeting the needs of Black/African-American cancer patients and caregivers. Similarly, this report makes no attempt to consider the rapid progress of artificial intelligence innovation and utilization in the field of psychosocial support.

Small sample size

This survey yielded a very small sample size. Insights gained from the survey could be limited, and it may not be appropriate to generalize conclusions. This is a preliminary effort as we consider this the first of many steps that CSC will be taking as part of its commitment to more equitable service delivery.

Conclusion

Cancer affects people in every community. Some communities, however, suffer more than others. In particular, Black/African-American communities have higher incidence of cancer, shorter survival times, and higher mortality rates. Many factors have gone into creating social, economic, and environmental conditions that cause these harsher outcomes. This creates a public health crisis that not only affects a single community, but which has a ripple effect regionally and across society at large. No single organization or program can fix the social, economic, and environmental problems that fuel this crisis.

There are programs and services, however, that have been shown to improve health outcomes and quality of life after a cancer diagnosis. To date, these programs have not been tailored to under-resourced communities and communities of color, even though those groups have been shown to need and want such support as well as the benefits of support programs.

To help mitigate the cancer outcome disparities in those communities, nonprofit, civic, social, corporate, faith-based, and government groups must collaborate to make not only healthcare equitable and available to all, but also the type of psychosocial and support programs that Cancer Support Community provides.

This can be accelerated by more deeply understanding the unique needs of each community; by involving members of that community in outreach and program delivery; by providing additional assistance such as financial and logistical support in order to ameliorate the barriers to participation; and by creating coalitions across government, nonprofit, faith-based, corporate, and community organizations that can share knowledge, expertise, and resources in working to fix this community health crisis.

The unmet needs of cancer patients and their family members and caregivers in under-resourced communities have been dramatically brought to light over the past few years, and we are just now starting to truly understand the scope of these disparities. As the number of cancer survivors increases every year it is vital that the lack of cancer support is viewed as a major public health issue impacting every aspect of our society. At Cancer Support Community, we are committed to bringing critical support programs and services to address health disparities in cancer care in all communities, and we welcome collaborations and partnerships to achieve this goal.

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About Cancer Support Community San Francisco Bay Area

Cancer Support Community San Francisco Bay Area provides free comprehensive support programs including counseling, support groups, nutrition, exercise, emergency financial assistance, and patient education programs as well as special programs for teens and children. Our evidence-based programs enable cancer patients and their loved ones to partner with their treatment team to improve health outcomes and quality of life. Programs are provided in-person and virtually, in English and Spanish. For more information visit www.cancersupport.net.

Cancer Support Community San Francisco Bay Area is devoted to incorporating the following commitment to health equity in all our actions as we work to fulfill our mission.

Cancer Support Community: Health equity in cancer care

While cancer does not discriminate, not all patients with cancer are treated the same. As an organization it is our goal to make sure that all cancer patients and their families, regardless of what community they are from, have access to support services that meet their needs so they can achieve better health outcomes and quality of life. We understand that finding solutions to achieving health equity in cancer care is complex, will take time, and will require building lasting and diverse partnerships as well as addressing both individual and systemic change. We will learn from both our successes and failures while always remaining committed to decreasing inequities in cancer care so that all cancer patients and their families feel part of our community.

Special thanks to:

Survey participants who took the time to complete the survey and share their experiences as a cancer patient and caregiver.

Ayaka Nakaji, LCSW, who researched and wrote this report as part of her work for completion of a master's in public health degree from UC Berkeley. Thank you for all your work and commitment to improving health equity in cancer care.

Anjali Sibley, MD, Cancer Support Community, Board of Directors, who developed the original concept for this report.

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