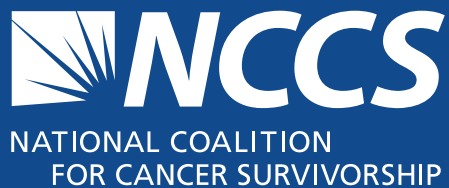


STATE OF SURVIVORSHIP

SURVEY: 2021

DISPARITIES IN QUALITY OF CARE



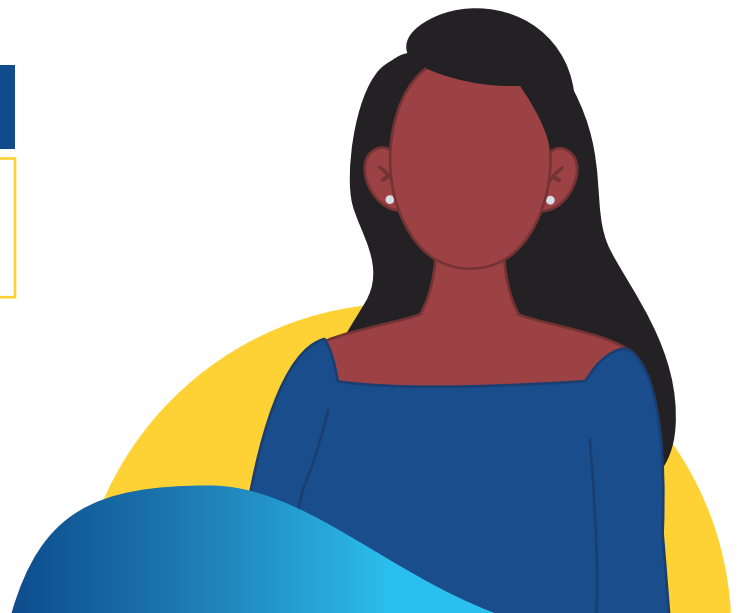
DISPARITIES IN QUALITY OF CARE

Most cancer patients describe their cancer treatment and care as excellent and believe their health care providers (HCPs) were approachable, respectful, and coordinated their care well. Though for many, their threshold is making it through their treatment. But there are consistent disparities, with younger, Hispanic/Latino, female, and low-income patients having consistently poorer experiences. There are also differences between metastatic patients and those still in treatment, compared with those who have completed treatment.

Camila is a mother of two and was 32 when she was diagnosed with Stage II ovarian cancer. Her struggle to get a proper diagnosis is one shared by many younger cancer patients, as well as Hispanic/Latino patients. She had pain in her right ovary and was given a variety of diagnoses, including a urinary tract infection, bladder infection, and bacterial infection. After months of her pain worsening while on antibiotics, and multiple visits to urgent care and her primary care physician, she refused to leave her provider's office and insisted on an ultrasound. The transvaginal ultrasound showed a 12cm tumor that turned out to be cancerous.

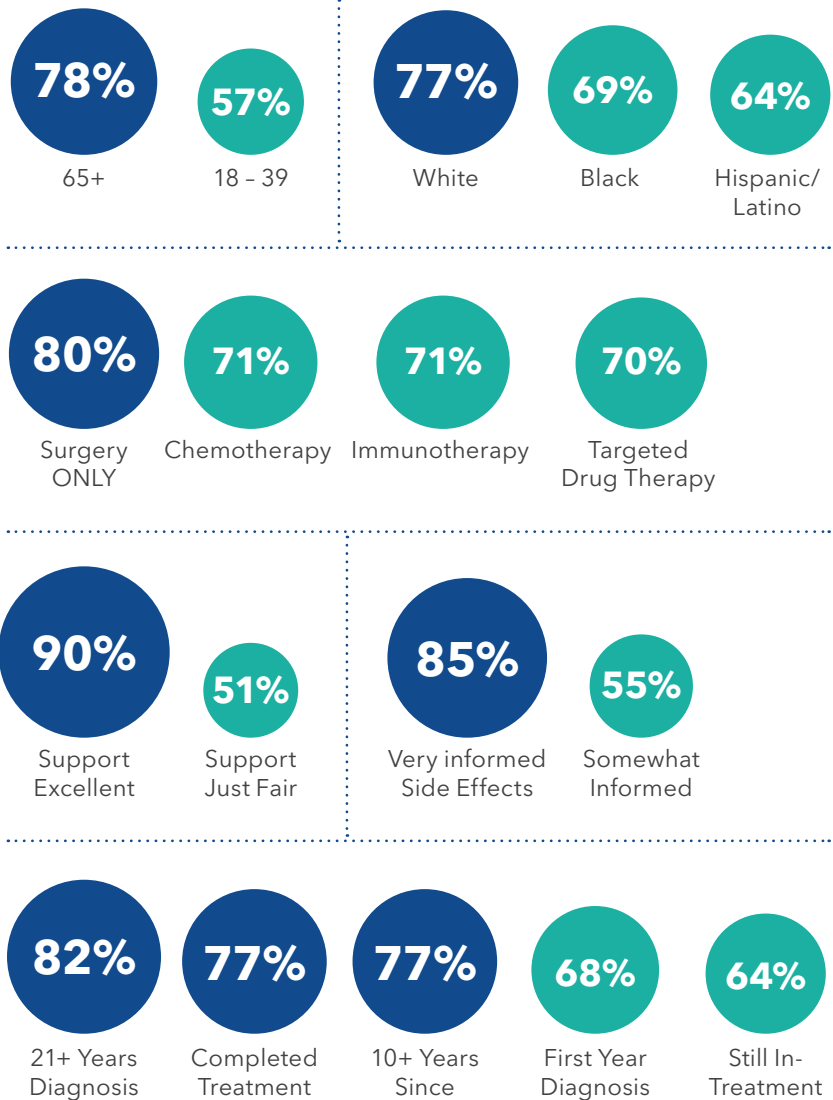
"I am alive, period."

#1 Reason to describe cancer treatment and care as excellent.



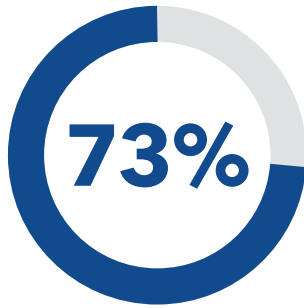
Even with the substantial challenges she faced in receiving a diagnosis, Camila felt her treatment was excellent. She did have many questions throughout, but said her HCPs were able to answer them and they listened to her concerns with care. She is part of the 64% of Hispanic/Latino patients who rated their care as excellent. However, compared to 69% of Blacks and 77% of whites who rated their care as excellent, there is a clear difference in satisfaction with their care.

Respondents Who Rated Their Cancer Care as Excellent



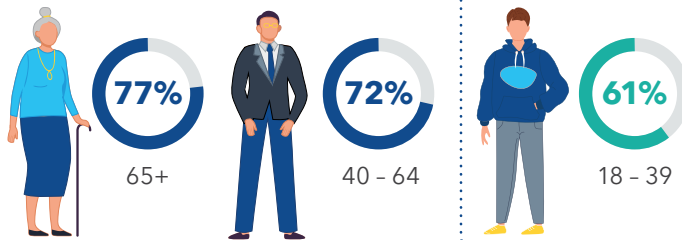
Differences were evident in patients' relationships with their HCPs. When asked if they felt their HCPs listened to their questions and concerns, only 63% of Hispanic/Latino patients said yes compared to 75% of their white and 73% of their Black counterparts.

Relationships with Health Care Providers



Felt their HCPs respected their questions and concerns

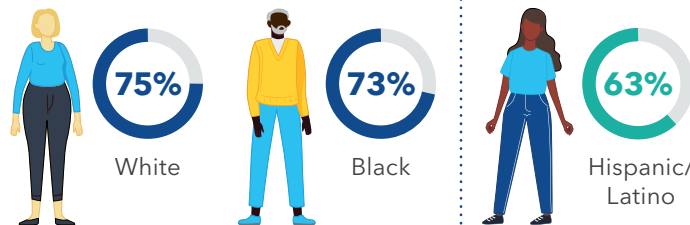
AGE DIFFERENCES



I feel like they keep things from me because I won't understand.

They were always in a rush or assumed I didn't know what I was talking about, meanwhile I am a health care professional myself.

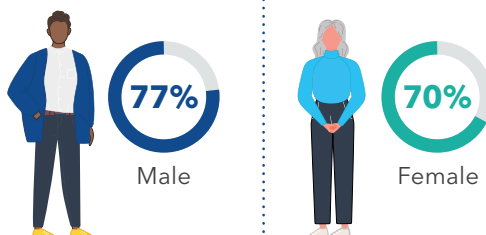
ETHNIC DIFFERENCES



Again, some of the doctors, all of them white and male, seemed to project their biases onto me.

Sometimes, my doctors would simply ignore my questions or even give me attitude if I had a lot of questions.

GENDER DIFFERENCES



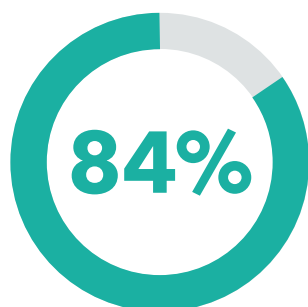
He kept telling me I was overreacting and to follow up in 6 months.

Dismissing me out of hand regarding pain—don't feel as a middle-aged woman I am heard.

"Oh yeah, that happens." Not even a word of sympathy or encouragement.

As Camila went through surgery to remove her tumor and her subsequent chemotherapy, she said she felt heard, particularly by her chemotherapy nurse who was with her throughout the process. She was informed of the myriad side effects that were possible and did in fact experience several, including hair loss, nausea, extreme fatigue, and muscle and joint pain. While almost all patients experience at least one side effect, the data show again that female, Hispanic/Latino, younger and low-income patients are more likely to experience many of the side effects.

Top Symptoms Experienced

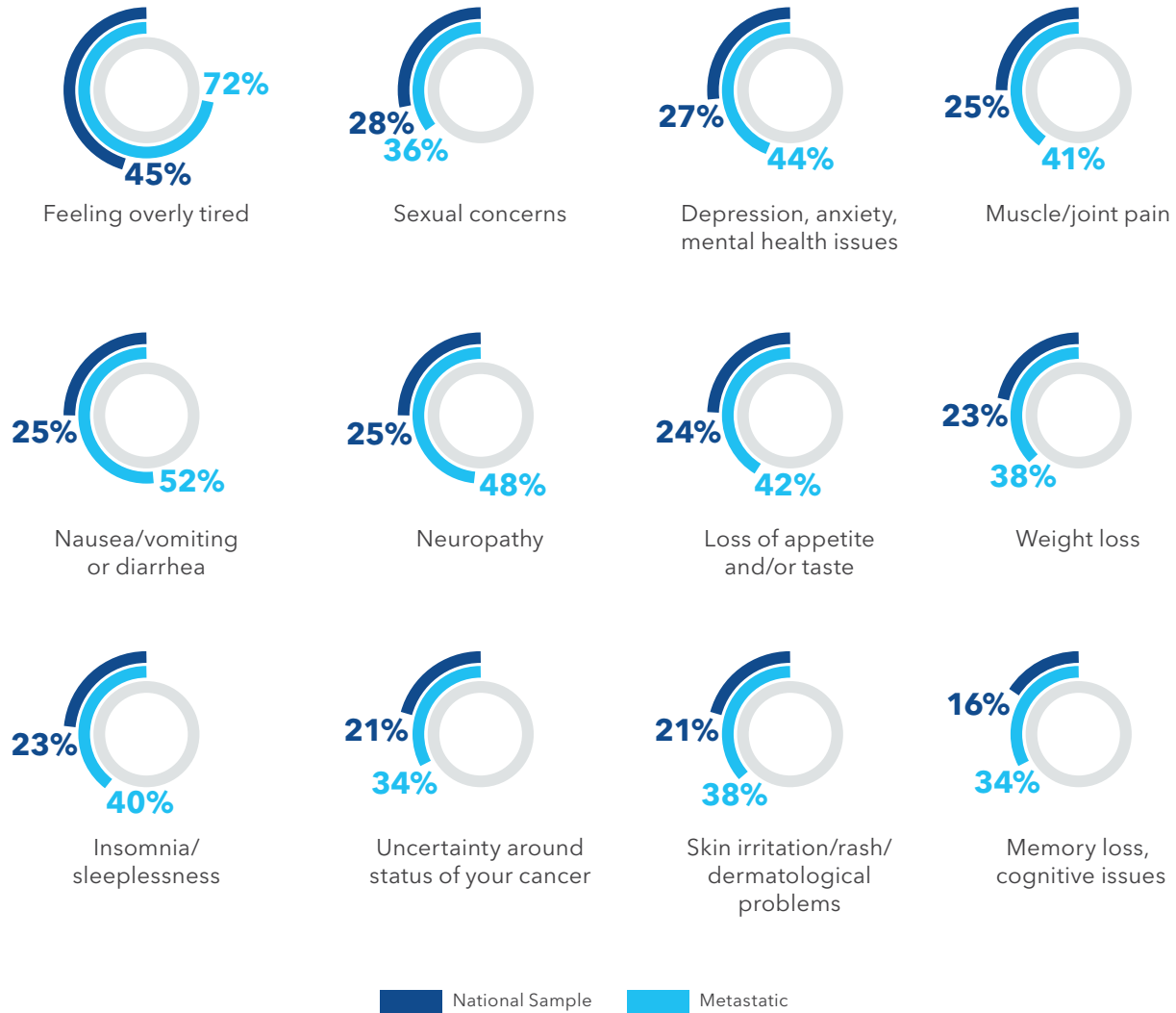


of Patients experienced at least one symptom

	National Sample	Male	Female	18 - 39	Hispanic/Latino	Low Income
Feeling overly tired	45%	34%	56%	61%	53%	57%
Sexual concerns	28%	38%	19%	27%	26%	17%
Depression, anxiety, mental health issues	27%	17%	37%	52%	43%	43%
Muscle/joint pain	25%	16%	34%	39%	33%	40%
Nausea/vomiting or diarrhea	25%	17%	33%	56%	33%	38%
Neuropathy	25%	18%	31%	40%	28%	33%
Loss of appetite and/or taste	24%	18%	30%	48%	32%	34%
Weight loss	23%	24%	23%	53%	38%	31%
Insomnia/sleeplessness	23%	14%	31%	40%	36%	28%
Uncertainty around status of your cancer	21%	21%	21%	26%	21%	28%
Skin irritation/rash/dermatological problems	21%	12%	29%	30%	22%	22%
Memory loss, cognitive issues	16%	7%	25%	33%	30%	24%

Not surprisingly, side effects are more commonly reported by metastatic patients. Of the 12 top side effects reported, metastatic patients experienced all or most of them at an average of 18 percentage points more than other respondents. Fatigue and nausea were each experienced by 27 percentage points more by metastatic patients than non-metastatic.

Metastatic Patients Experience More Symptoms than the National Sample



While two-thirds of patients felt informed about side effects, in most cases less than half felt their HCPs were very helpful in addressing them. The side effects HCPs were most helpful with were nausea/vomiting or diarrhea and dermatological issues, both of which have effective treatments. This suggests room for improving how to address more nuanced side effects of cancer treatments, particularly memory loss and cognitive issues (30% reported their HCPs were very helpful), sexual concerns (35% said their HCPs were very helpful), and fatigue, the top reported symptom (46% reported their HCPs were very helpful).

These findings are consistent with our surveys from 2019 and 2020. Of note, the percentage of respondents who said their HCPs were very helpful went up in 2021 for a number of the top symptoms reported.

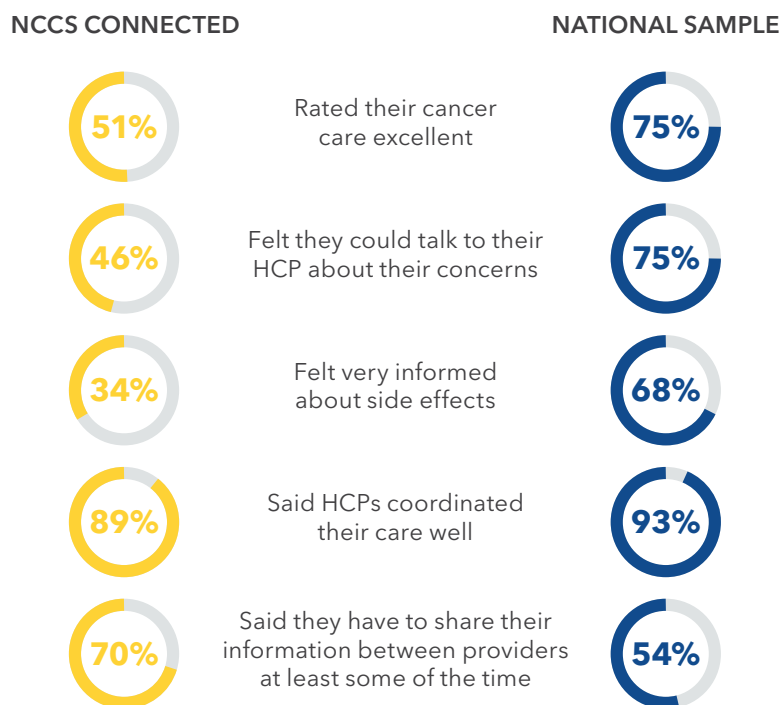


While two-thirds felt informed about side effects, in most cases less than half believe their HCP was very helpful in addressing them.

Once Camila finished her chemotherapy, she began regimented two-month check-ins for scans and bloodwork. More than two years into her post-treatment care, her doctors continue to find no evidence of disease. Interestingly, while 75% of respondents said their cancer care was excellent, only 63% say the same about their post-treatment care. That percentage is much lower among NCCS-connected respondents with only 38% saying their post-treatment care is excellent.

Survivors connected to NCCS in the survey were, as a whole, less satisfied with their care compared to the national sample on a range of measures, including quality of care, coordination of care, feeling informed about side effects and communication with HCPs.

Higher Expectations/Lower Satisfaction for Connected Patients



The data show that the work NCCS does to help survivors advocate for equity in, and access to, quality care helps them look at their treatment and post-treatment with a critical eye of what “quality care” truly means. The data also show we have much work to do to increase opportunities for quality care for all who are touched by cancer.





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