

NCCS 2020 SURVIVORSHIP SURVEY

OVFRVIEW OF SURVEY FINDINGS



"Doctor knows best" about treatment is the prevailing mindset of cancer patients nationally. By almost a 3-to-1 margin, cancer survivors are more likely to rely on their doctor to tell them what treatment option was best (61%) versus being involved in the research and decision (22%). And, those who report being more involved in initial treatment decisions tend to have more positive post-treatment experiences.



Patients who are "connected" to an advocacy group, like NCCS, are clearly a different audience. They have higher expectations of their care and health care providers. They are also more interested in a range of resources to help them with decision-making and self-advocacy.



Side Effects

Fatigue and mental health issues are the most common side effects reported by cancer patients and survivors. Few feel their health care providers were very helpful in addressing these during treatment, and most report their doctors did not bring up these key aspects of functional status during post-treatment care.



Demographic Differences

There are a few key audiences whose post-treatment concerns are greater: younger cancer patients/survivors, African Americans, Hispanics, females, and chemotherapy patients.



Concerns

Nationally, survivors' tops concerns are maintaining a healthy weight, getting enough exercise, being there for friends and family, cost of medical care, and having enough energy to make it through the day. But few patients found their health care providers to be very helpful on any of these.

MOST CANCER PATIENTS SAY THEY RELY ON **DOCTORS TO MAKE TREATMENT DECISIONS**

"I rely/relied on the doctor to decide on treatment options and chose the best course of action'

61% describes

"Somewhere in the middle 18% describes

"I am/was very involved in researching and deciding on the best treatment options for me

22% describes



SURVIVORS' TOP CONCERNS ARE ABOUT PHYSICAL HEALTH ISSUES, THE FUTURE, AND THE COST OF MEDICAL CARE

Top Concerns: % concerned Maintaining a healthy weight Getting enough exercise Being there for friends and family Cost of medical care Having energy to make it through the day









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55% of cancer patients who report being involved in treatment decisions felt better prepared for post-treatment.



Majority of cancer patients say they discussed what to expect post-treatment with their provider (62%), but far fewer got information about exercise and nutrition (39%), long-term side effects (39%), or mental health support (24%). Only 17% report getting a post-treatment survivorship plan.

TAKEAWAYS: ADVICE FROM CANCER SURVIVORS

"Stuff they didn't tell me during treatment to help with nausea, sores, muscle pain. I couldn't lift my head-was not prepared. Tell patients that it's normal to have anxiety and depression after chemo."

- Female, 65, Lymphoma NH

"What's worked for me is to think of it as a job that you push through. Make a check list, celebrate each victory, got to focus on the end point, take control of what you can, and let go of what you can't."

- Female, 29, Breast

"Trust the process and listen. Just continue to move forward and get it out of the way." - Male, 29, Testicular

"I would tell them to keep your faith because you need that. Think about your outcome. I would tell them to fight as hard as you can. And prepare yourself for the biggest fight of your life. It feels like your body betrayed you, so now you have to fight. Keep your head up and keep trucking. Cancer is not going to overcome you."

- Female, 39, Breast

"Pick doctors who will spend time with you and answer your questions. Find someone who is understanding and willing to listen." – Female, 71, Lung

DEMOGRAPHICS



Age	
18-44	9%
45-64	38%
65+	52%



Single	13%	
Married		54%
Divorced	14%	
Other	18%	

Race/Ethnicity	
White	81%
African American	10%
Hispanic	8%
Asian	3%
American Indian	1%