

The 2020 State of Cancer Survivorship

Wisdom from the Survivor Perspective



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Today's Insights

- **Updates from the Community Oncology Alliance (COA) & COA's Patient Advocacy Network (CPAN)**
- **2020 State of Cancer Survivorship:** Understanding the patient experience and insight into the post treatment survivor experience

To learn more about:

COA's Patient Advocacy Network: www.coaAdvocacy.org

Community Oncology Alliance: www.communityoncology.org

National Coalition for Cancer Survivorship: www.canceradvocacy.org



Cancer Survivorship Study

Findings from In-depth Interviews and National Surveys of Cancer Patients and Survivors

August 2020



Methodology

Phase 1

In-depth Interviews with Cancer Patients and Survivors

- Fifteen (15) virtual interviews, approximately 60 minutes-each, March 2020
- Diagnosed within the last 2 years; mix of stages and cancer types
- Nationwide recruit: mix of age (half over 65+), race/ethnicity, income (half low income, half middle-upper)

Phase 2

Nationwide Survey of Adult Cancer Patients and Survivors

- Nationwide sample of n=840, fielded April 15-May 1, 2020
- Oversamples of Blacks, Hispanics, low income, 65+ to analyze these groups with more statistical reliability
- Set quotas to make sure representative of US cancer population: age, gender, race/ethnicity, and region (re: ACS and NCI)
- Used Dynata, a non-probability online panel provider

Phase 3

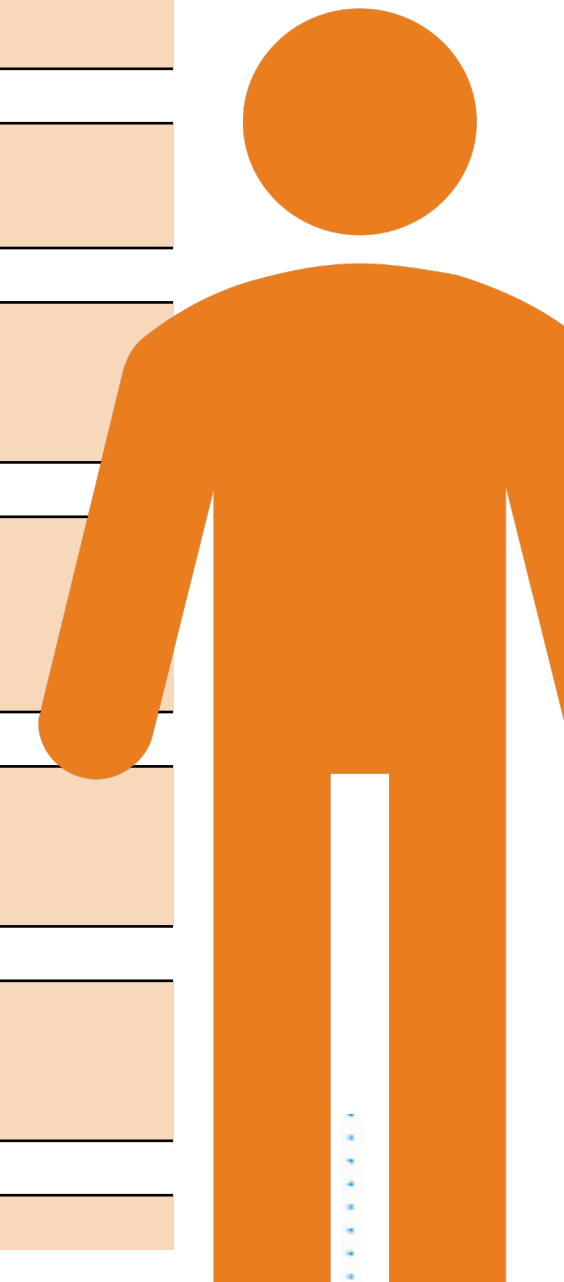
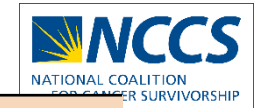
Nationwide Survey of “NCCS Connected” Patients and Survivors

- Nationwide sample of n=479, same field period as above
- Emailed invitation to all NCCS email contacts, inviting them to take the survey + 2 reminders

Blue/red = statistically **higher/lower** by audience
Full text of survey questions is in the notes section of slides

National Sample

NCCS Connected



Gender

49% Male 51% Female	16% Male 84% Female
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Age

9% Age 18-44 38% Age 45-64 52% Age 65+	13% Age 18-44 53% Age 45-64 31% Age 65+
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Education

19% Less than college 32% Some college/2-year degree 26% Bachelor's degree 22% Postgraduate degree	3% Less than college 24% Some college/2-year degree 26% Bachelor's degree 48% Postgraduate degree
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Income

17% Less than \$25k 26% \$25k-\$50k 20% \$50k-\$75k 14% \$75k-\$100k 20% More than \$100k	10% Less than \$25k 14% \$25k-\$50k 14% \$50k-\$75k 15% \$75k-\$100k 35% More than \$100k
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Insurance

56% Medicare 13% Medicaid 24% Private/employer 6% Private/spouse or parents	38% Medicare 5% Medicaid 43% Private/employer 13% Private/spouse or parents
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State of Physical

7% Excellent 50% Good 37% Fair 6% Poor	10% Excellent 59% Good 25% Fair 5% Poor
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Treatment

43% had Chemotherapy	75% had Chemotherapy
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Overview of Findings



Mindset

“Doctor Knows Best” about treatment is the prevailing mindset of cancer patients nationally, and majorities say they are satisfied with their care. But if you go a layer deeper, there are cracks in this foundation. And those who report being *more* involved in treatment decisions tend to have more positive post-treatment experiences.



Expectations

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



Side Effects

Fatigue and mental health issues continue to be the most common side-effects. Few feel their HCP’s are very helpful in addressing these during treatment, nor do most doctors bring-up these key aspects of functional status during post-treatment care.



Concerns

Survivors are most concerned about a range of physical health and financial issues. These continue to be areas where they do not get a lot of support from their health care team. There is interest in a website where info can be customized by cancer type.



Demographic Differences

Across the survey, there are a few key audiences whose post-treatment concerns are greater: younger, Blacks, Hispanics, women, and chemotherapy patients.

Nationally, Most Cancer Patients Say They Rely on Doctors to Make Treatment Decisions

- By almost a 3-to-1 margin, cancer patients/survivors nationally say that they relied on their doctor to tell them what treatment option was best, vs. being involved in the research and decision.



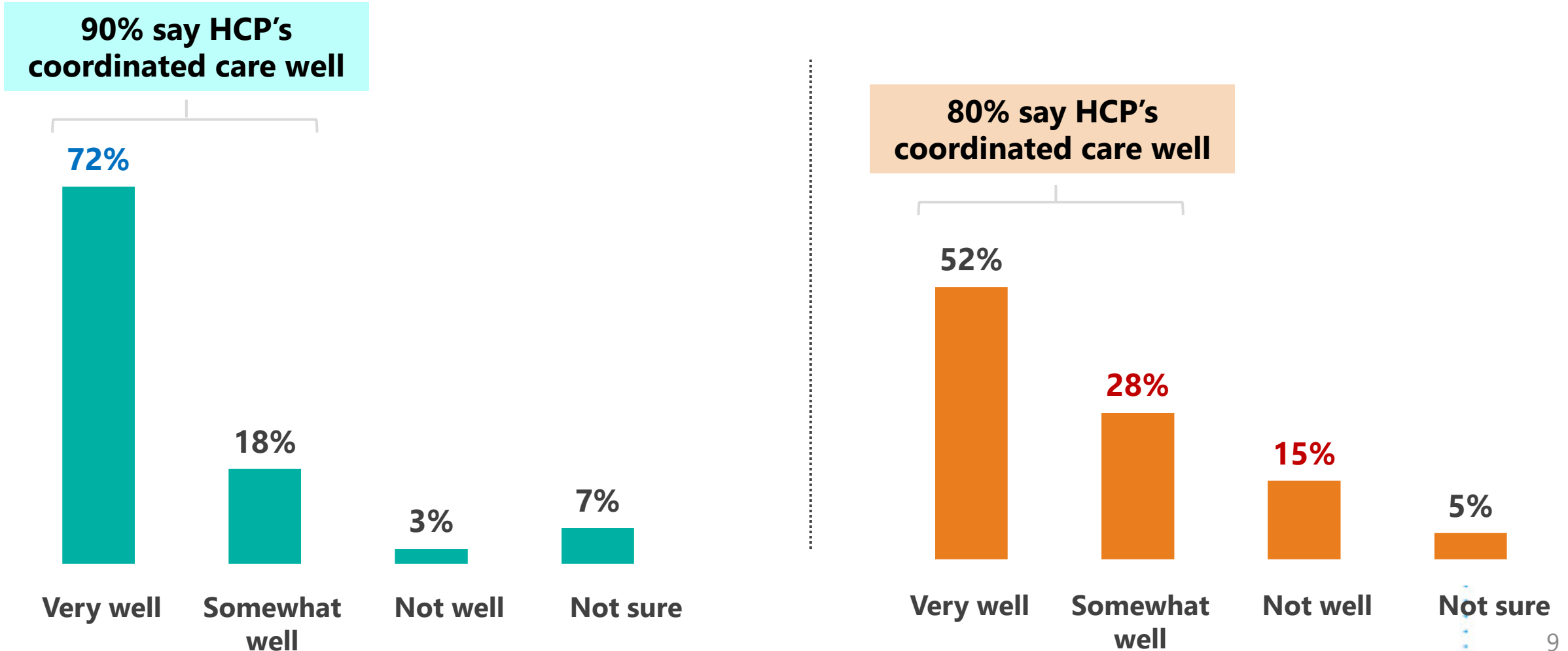
Please think about your mindset and experiences as a cancer patient. For each set of statements, select the statement that describes you best, or if you are somewhere in the middle.

The Survey Suggests that Initial Involvement Helps Improve Post Treatment Care Experiences

Patients Who Report Being Involved in Treatment Decisions	Patients Who Report Relying on their Doctor
Felt prepared for post treatment, 55%	Versus 50%
Spoke to their HCP about post-treatment care, 53%	Versus 40%
Describe their post-treatment medical care as "excellent," 59%	Versus 50%













Most Cancer Patients Nationally Believe their HCP's Did a Good Job Coordinating their Care

- Those who are connected to NCCS are less likely to feel this way strongly and are generally have higher expectations of health care professionals.



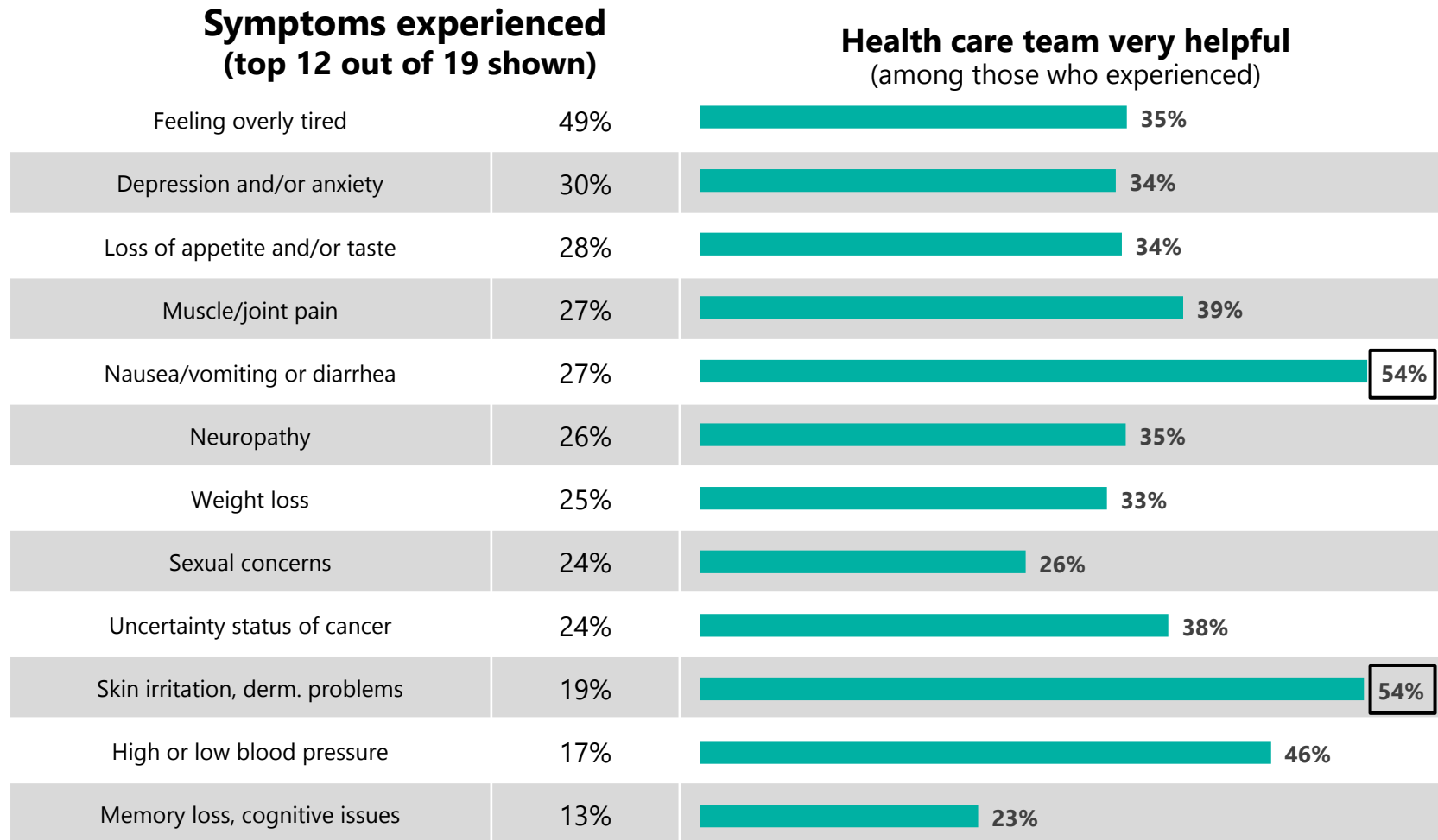
Fatigue & Depression Are Most Common Side Effects

Symptoms experienced (top 12 out of 19 shown)

		18-39	40-64	65+	Male	Female	Black	Hispanic	Low income	Chemo	Treatmt 6+ years
Feeling overly tired	 49%	63%	60%	39%	37%	61%	52%	60%	53%	72%	48%
Depression and/or anxiety	 30%	50%	44%	17%	21%	39%	36%	46%	39%	41%	32%
Loss of appetite and/or taste	 28%	45%	35%	20%	19%	36%	27%	46%	33%	52%	27%
Muscle/joint pain	 27%	42%	35%	19%	18%	37%	31%	39%	32%	43%	24%
Nausea/vomiting or diarrhea	 27%	48%	38%	15%	16%	37%	33%	41%	38%	51%	26%
Neuropathy	 26%	33%	37%	16%	19%	33%	36%	37%	30%	47%	21%
Weight loss	 25%	42%	29%	20%	24%	26%	27%	37%	29%	43%	25%
Sexual concerns	 24%	34%	26%	22%	28%	20%	32%	31%	19%	27%	25%
Uncertainty status of cancer	 24%	28%	28%	20%	25%	23%	17%	31%	23%	25%	16%
Skin irritation, derm. problems	 19%	24%	23%	16%	14%	24%	14%	23%	28%	23%	15%
High or low blood pressure	 17%	24%	18%	15%	16%	18%	18%	11%	22%	21%	14%
Memory loss, cognitive issues	 13%	16%	21%	7%	5%	21%	9%	19%	20%	26%	14%

Source=National Sample, n=840

Going a Layer Deeper, Less Than Half Say Their HCP Was Helpful Addressing *Specific* Side Effects

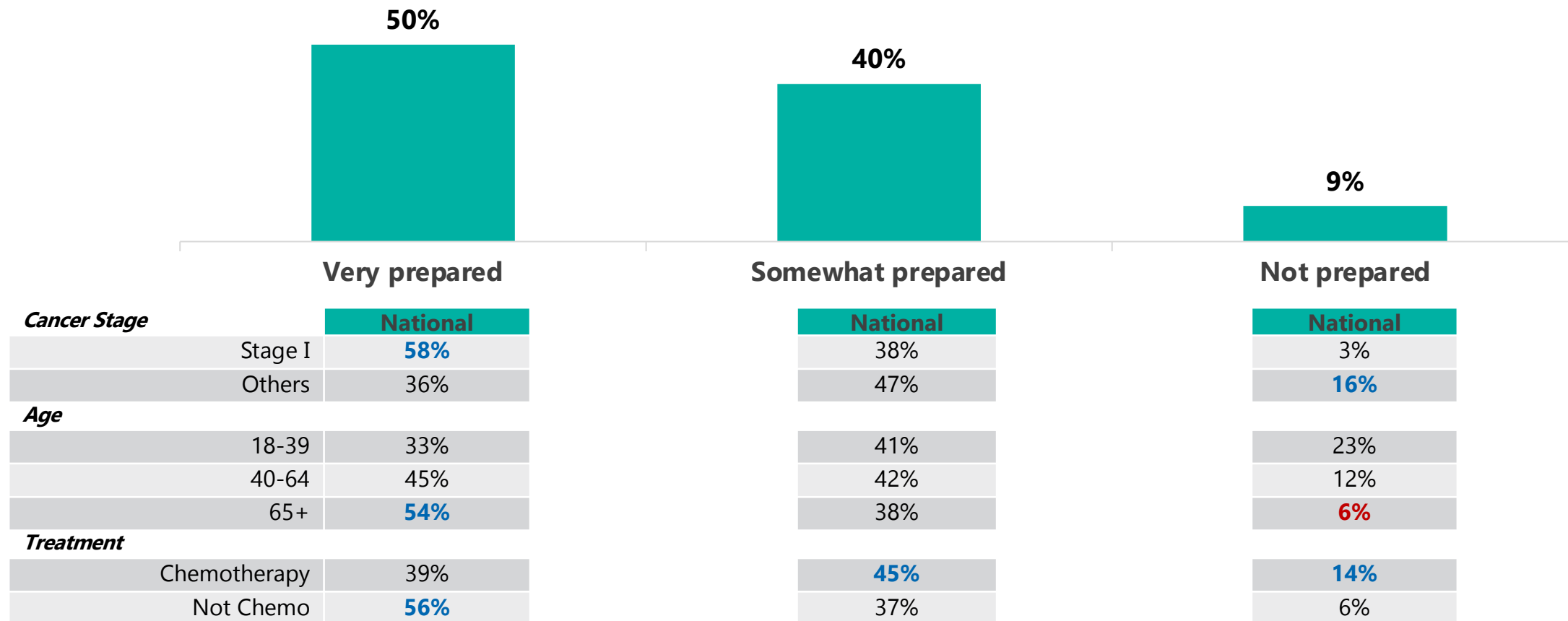


What bothered me, you have heavy doses of chemo which affects your body, but no one says it will affect your brain. When I mentioned to my oncologist that I was depressed and anxious, knot in my stomach, shaking. He'd say this is very normal, it will go away. - Female, 65, Lymphoma NH

Half of Patients Describe Themselves a “Very Prepared” for Post-Treatment

- Younger patients, those in later stage cancers, and those who had chemo are less confident.

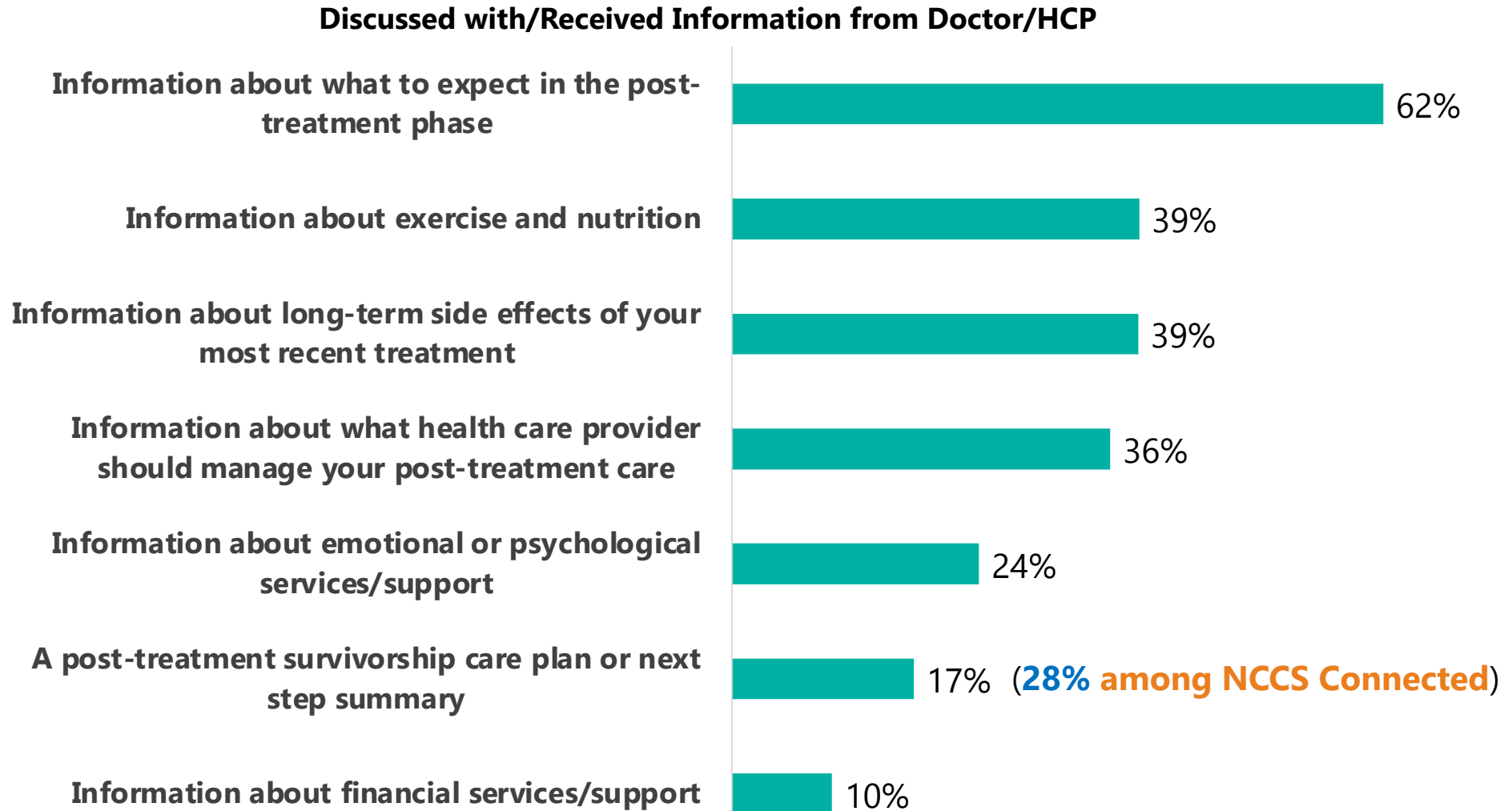
How well prepared for transition to Post-Treatment



Source=National Sample, n=638

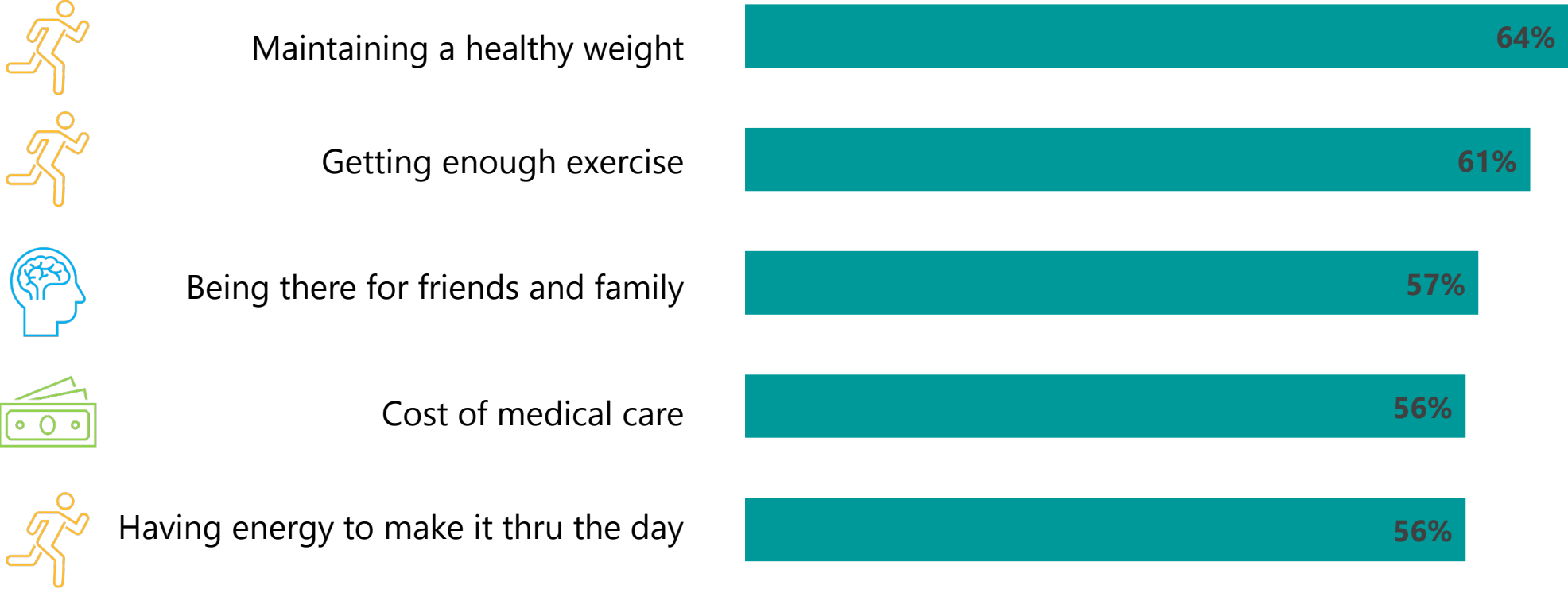
Majorities Discussed What to Expect Post-Treatment; Fewer Got Additional Information

- Few report getting a post-treatment survivorship plan (although this is significantly higher among the NCCS Connected audience).



Survivors' Top Concerns Are about Physical Health Issues, the Future, and the Cost of Medical Care

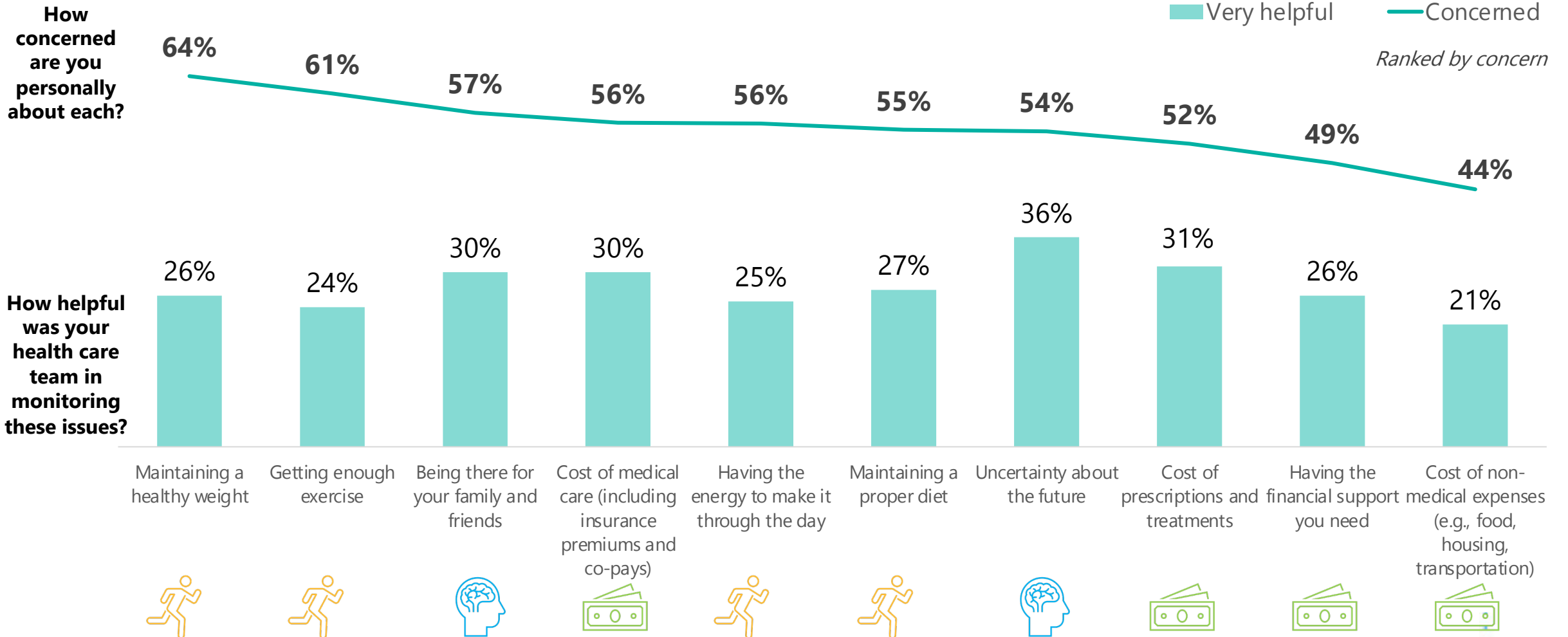
Top Concerns: % concerned



 Physical health/adherence  Financial/Insurance  Emotional/Lifestyle

Source=National Sample, n=840

Nationally, there Are 10 Key Concerns (Mostly Physical and Financial) Where Few Patients Found their HCP's Very Helpful



Thank You to Shelley Fuld Nasso and Our Listeners!

Don't miss our next advocacy chat
Wednesday | 12pm | December 9, 2020

Between Life and Death from despair to hope



Kashyap Patel, MD
Chief Executive Officer
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