



# Annual State of Survivorship Study

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

June 2021



## Research Objectives and Questions

**Continue to delve into the cancer patient and survivor journey from a range of perspectives, to better understand how NCCS can support its mission to advocate for quality cancer care for all**

# Methodology

## Phase 1

### **In-depth Interviews with Cancer Patients and Survivors**

- Sixteen (16) virtual interviews, approximately 60 minutes-each, March 2021
- Mix of Stage IV/Metastatic patients and low income/socio-economic status
- Nationwide recruit: mix of race/ethnicity, years living with cancer, cancer types, and where they live (urban, suburban, or rural)

## Phase 2

### **Nationwide Survey of Adult Cancer Patients and Survivors**

- Nationwide sample of n=1104, fielded May 5-May 24, 2021
- Set quotas to make sure the sample was representative by age, gender, race/ethnicity, and region (using ACS and NCI data)
- Oversamples of Stage IV/Metastatic patients to analyze this group with more statistical reliability
- Surveys were recruited through an online non-probability sample with quotas set to ensure demographically representative audiences, following AAPOR best practices

## Phase 3

### **Nationwide Survey of “NCCS Connected” Patients and Survivors**

- Nationwide sample of n=500, same field period as above
- Emailed invitation to all NCCS email contacts, inviting them to take the survey + 2 reminders

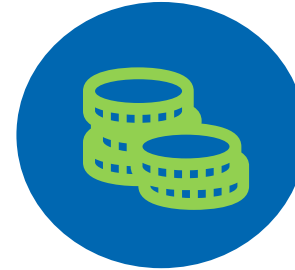
# Overview: Topics Covered



**Mindset Shift**



**Disparities in Care**



**The Costs of Cancer**



**Support Systems**




**Treatment During  
COVID**



**The Meaning of  
“Survivorship”**

# Pluralities say they relied on their doctor to make their cancer treatment decisions, though this number decreased dramatically from just a year ago

2020		2021
61%	I rely/relieved on the doctor to decide on treatment options and chose the best course of action.	44% ▼
18%	Somewhere in the middle	22%
22%	I am/was very involved in researching and deciding on the best treatment options for me.	33% ▲



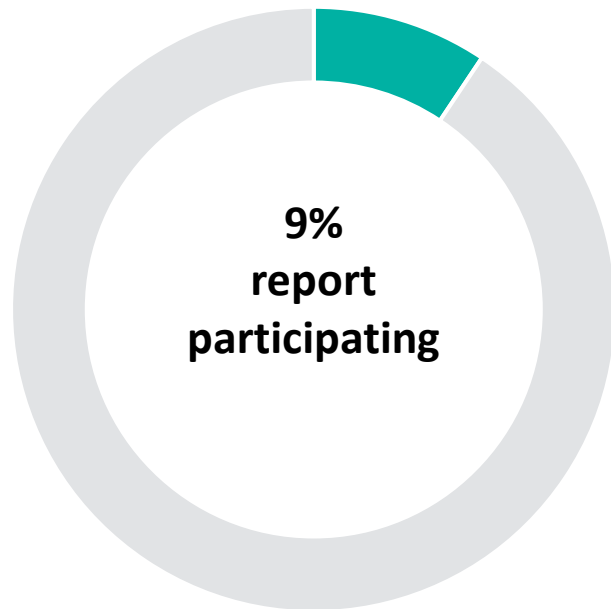
**More Likely to be Involved in Decision Making**

- Younger ages (18-29) **49%**
- Hispanic/Latino **45%**
- Urban **43%**
- Clinical Trial **47%**
- Immunotherapy **43%**
- Targeted Drug Therapy **41%**
- Palliative Care **46%**
- In-treatment **41%**
- College **37%**

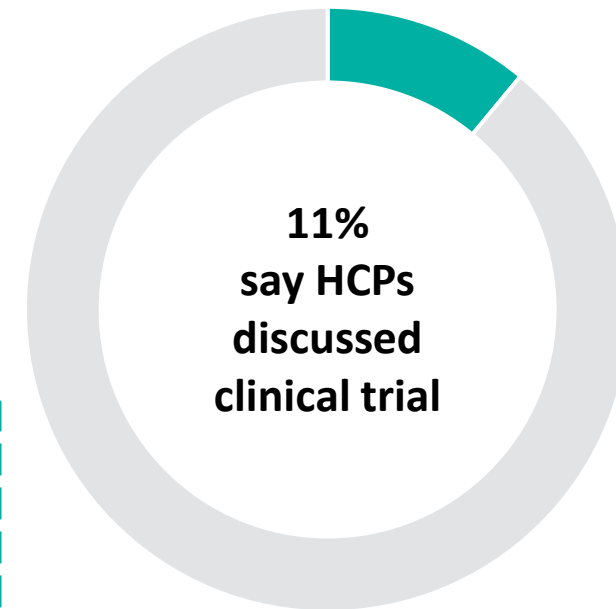
**NCCS Connected:** **43%** Very involved, 22% In the middle, **35%** Relied on the doctor

# Few patients are informed about nor are participating in clinical trials

At any point, did you participate in a clinical trial related to your cancer diagnosis?



Did your health care team offer/discuss a clinical trial with you?



**Higher for both among:**  
Younger  
Hispanic/Latino  
Urban  
Higher SES  
In-treatment  
Academic Medical Center  
Chemotherapy  
Targeted Drug Therapy  
Immunotherapy  
NCCS Connected



# Disparities in Quality of Care

## Respondents Who Rated Their Cancer Care as Excellent



of Patients describe their treatment and care as **EXCELLENT**



65+



18 - 39



White



Black



Hispanic/  
Latino



Support  
Excellent



Support  
Just Fair



21+ Years  
Diagnosis



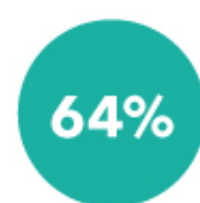
Completed  
Treatment



10+ Years  
Since



First Year  
Diagnosis



Still In-  
Treatment



Very Informed  
Side Effects



Somewhat  
Informed

# In addition to poor outcomes, several themes emerge among those who felt they had just good/fair/poor care

## **Income disparities:**

*To be honest, I'm poor. I just went with the program, tried not to bother anybody. (Hispanic/Latino, low income)*

## **Lack of Support and Coordination of Care:**

*No continuity. I see a different infusion nurse every time. I see a different NP every time. We discuss medication or scans, and they never get ordered. Insurance companies and doctors' offices don't communicate. No one seems to know me. (Metastatic)*

## **No Options nor Voice:**

*I do not feel that I was even consulted about options, because I was young and considered not smart enough to be in charge of my own care. I feel like when I finished treatment I was just dumped. There was very little care given to how I would have a lifetime of survivorship ahead of me. No one even wanted to hear about complications I was having, even though some ended up being early signs of poor lifelong outcomes. (18-39)*



# Majorities feel like their HCPs were approachable and respectful, but there are key demographic differences

Again, there are ...

## Age differences (**61%** 18-39, **72%** 40-64, **77%** 65+):

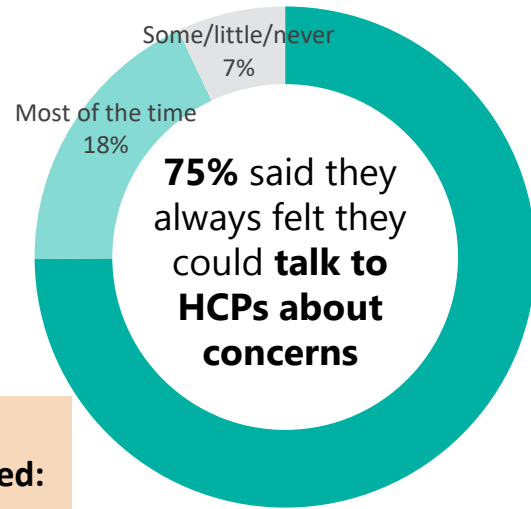
- *They were always in a rush or assumed I didn't know what I was talking about, meanwhile I am a healthcare professional myself. (18-39)*

## Ethnic differences (**75%** White, **73%** Black, **63%** Hispanic/Latino):

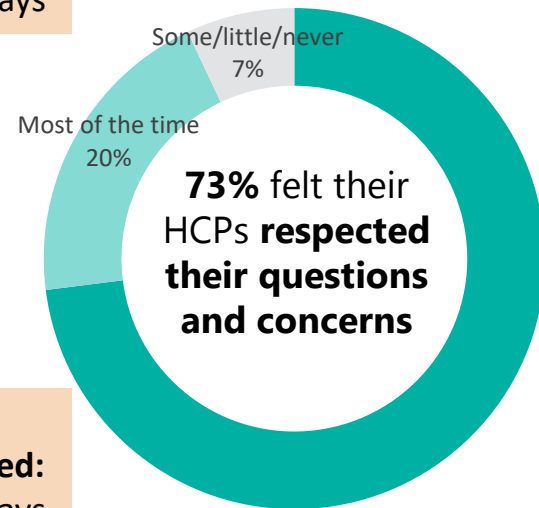
- *Again, some of the doctors, all of them white and male, seemed to project their biases onto me. (Hispanic/Latino)*

## Gender differences (**77%** Male, **70%** Female):

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



NCCS  
Connected:  
**46%** Always



NCCS  
Connected:  
**41%** Always

# Disparities in Quality of Care

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

# Costs of Cancer Care

## Hispanic/Latino and Younger Patients Have Higher Concerns



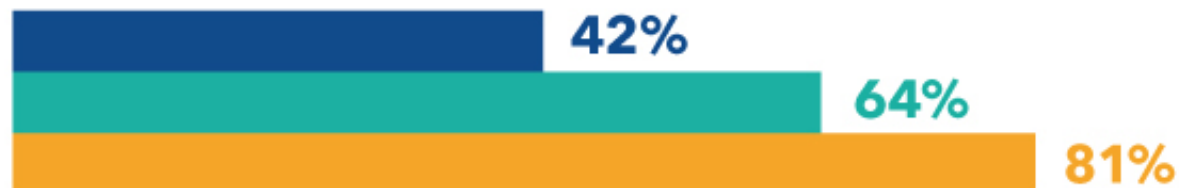
**PHYSICAL COST**  
Having energy to make it through the day



**EMOTIONAL COST**  
Uncertainty of future



**FINANCIAL COST**  
Having the financial support you need



 National Sample  Hispanic/Latino  18-39

# Women, younger, Hispanic/Latino, and low-income patients are more concerned about the range of issues

	Physical health/ adherence	Financial/ Insurance	Emotional/ Lifestyle	National Sample	Female	18-39	Hispanic/ Latino	Low Income
Maintaining a healthy weight				56%	63%	78%	73%	63%
Uncertainty about the future				56%	62%	85%	70%	67%
Having the energy to make it through the day				50%	57%	88%	65%	62%
Getting enough exercise				49%	55%	66%	62%	57%
Being there for your family and friends				48%	57%	78%	67%	55%
Managing ongoing side effects from treatment				47%	51%	78%	59%	54%
Cost of medical care (incl. insurance premiums and co-pays)				47%	53%	68%	50%	47%
Maintaining a proper diet				45%	51%	68%	63%	53%
Cost of prescriptions and treatments				43%	51%	68%	50%	46%
Having the financial support you need				42%	54%	81%	64%	56%
Having the emotional support you need				37%	47%	71%	61%	50%
Understanding the health insurance benefits available to you				37%	45%	66%	51%	40%
Support with mental health issues (e.g., anxiety or depression)				36%	44%	75%	57%	48%
Cost of non-medical expenses (e.g., food, housing, transport)				34%	42%	71%	50%	52%
Ability to maintain relationships with significant other, family, friends				33%	37%	66%	54%	41%
Support for your family and/or other caregivers				33%	39%	65%	49%	37%
Feeling isolated and lonely				33%	40%	72%	57%	49%
Getting/keeping health insurance				33%	43%	66%	48%	41%
Loss of income				32%	40%	81%	54%	44%
Long-term planning/career goals				32%	38%	78%	54%	38%
Change/decline in your interest in socializing with others				32%	38%	66%	54%	46%
Managing all of your prescribed medications and other treatments				30%	36%	66%	50%	37%
Cost of professional caregiving				29%	33%	55%	39%	34%
Visiting your doctor regularly				28%	34%	62%	46%	35%
Managing appointments				23%	30%	58%	41%	33%
Work/employment issues, like finding and keeping a job'				22%	29%	70%	46%	27%
Learning how to apply for grants, scholarships, or government benefits to help with medical and living costs'				21%	25%	65%	36%	32%
Getting/keeping disability insurance				20%	27%	57%	39%	31%
Starting a family/having children				9%	9%	54%	28%	10%

# Costs of Cancer Care

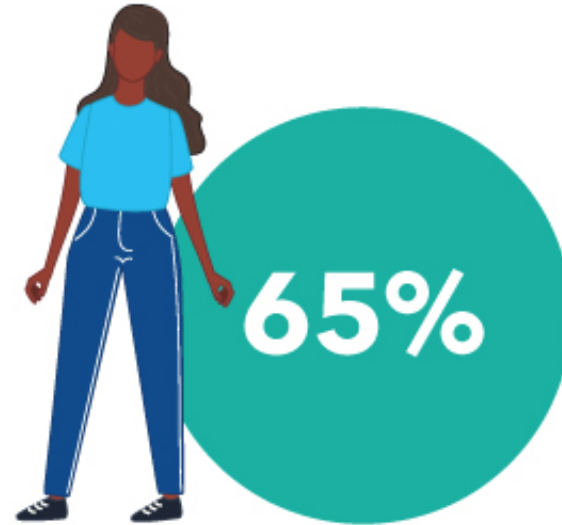
## Experienced Financial Sacrifices



National  
Sample



18 - 39

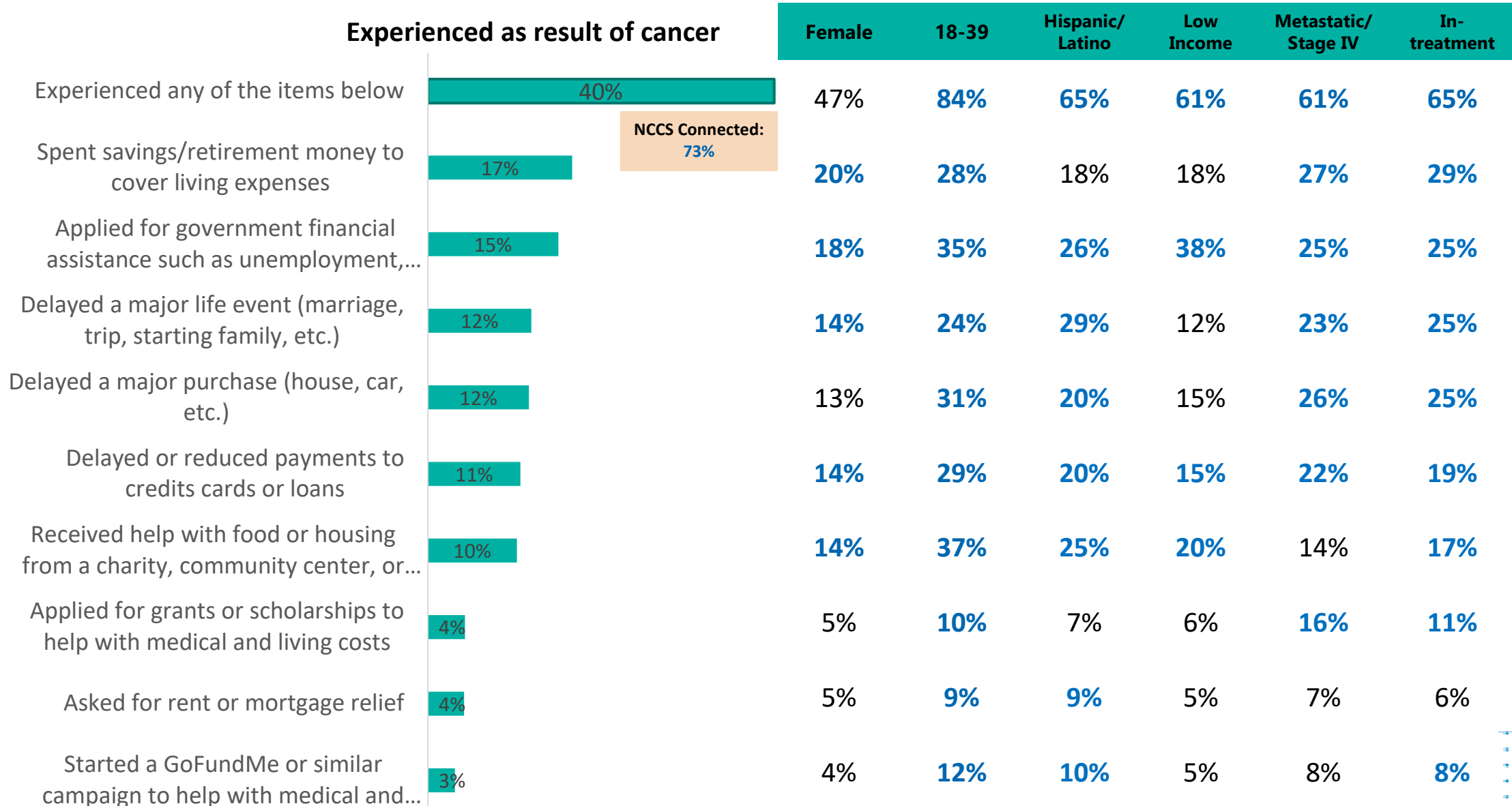


Hispanic/  
Latino



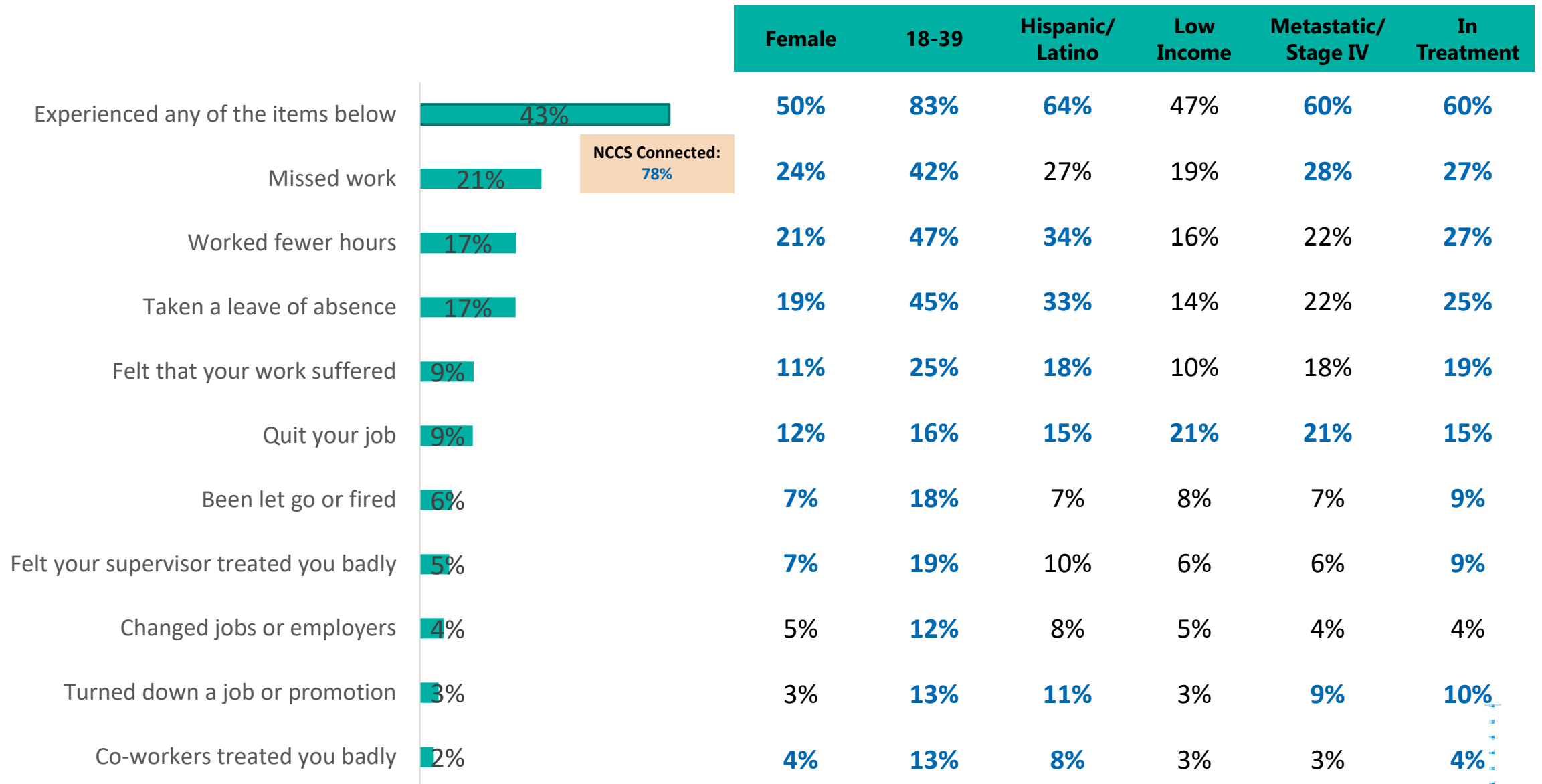
Metastatic/  
Stage IV

# Four-in-10 overall have made at least one of the following financial sacrifices, with numbers much higher among vulnerable audiences



Source=National Sample, n=1104

# Similarly, about 4-in-10 have seen their diagnosis impact their work status/environment, with similar groups reporting impact



Source=National Sample, n=1104