CANCER SUPPORT
COMMUNITY
CANCER EXPERIENCE REGISTRY

CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S
CLUB

Cancer Experience Registry Patient Insights Report

2024

Table of Contents

Cancer Support Community's Cancer Experience Registry (CER)

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- Web-based research survey available to those impacted by cancer
- Provides an opportunity for cancer survivors and caregivers to friends and family with cancer to make their voices heard and share their stories
- Includes questions about quality of life, diagnosis and treatment, health care team communication, and psychosocial needs, among others
- **3668 cancer patients and survivors** completed the Cancer Experience Registry between October 2021 and August 2024

II. Participant Background & Clinical History

Participant Background

Sociodemographic Characteristics

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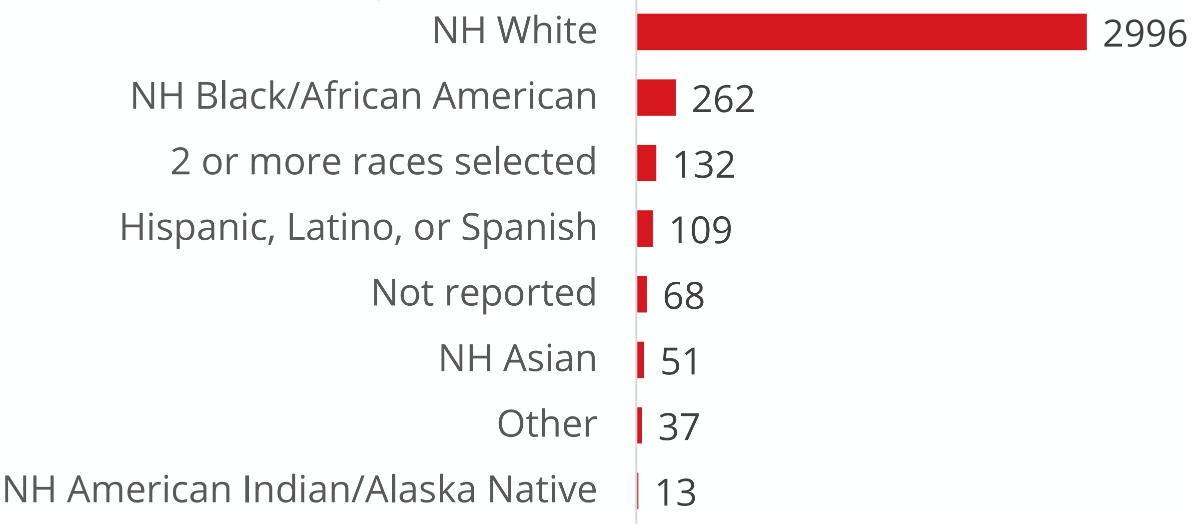
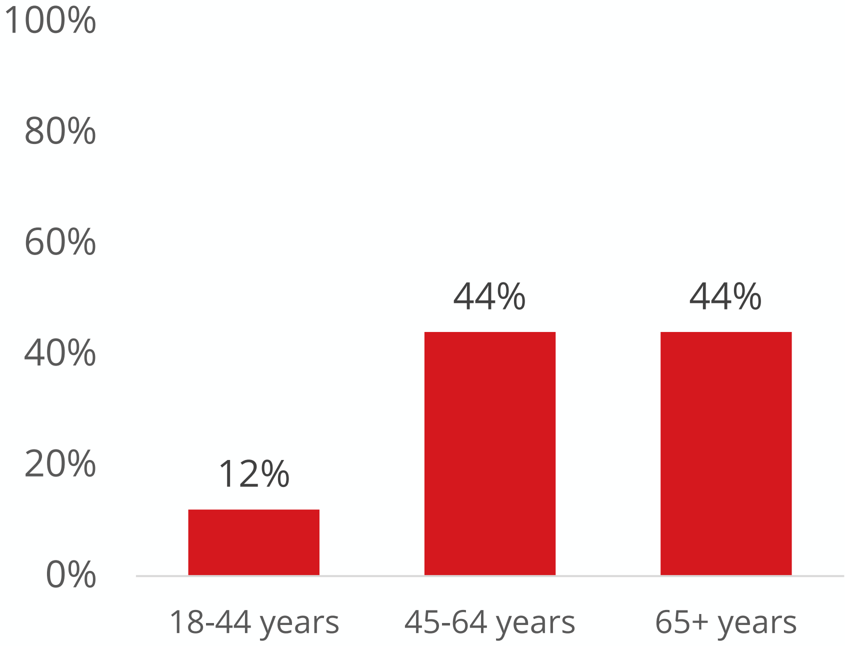
- Gender Identity
  - 896 Men (24%)
  - 2739 Women (75%)
  - 12 Other (<1%)
  - 21 Not Reported (<1%)

- Race & Ethnicity



- Age
  - Mean: 60 years old (SD=12.7)
  - Range: 19-93 years old



Note. NH = Non-Hispanic, Latino, or Spanish
n = 3668

Participant Background

Sociodemographic Characteristics

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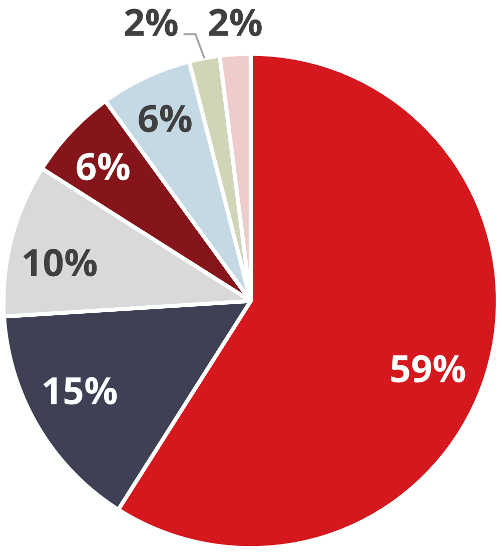
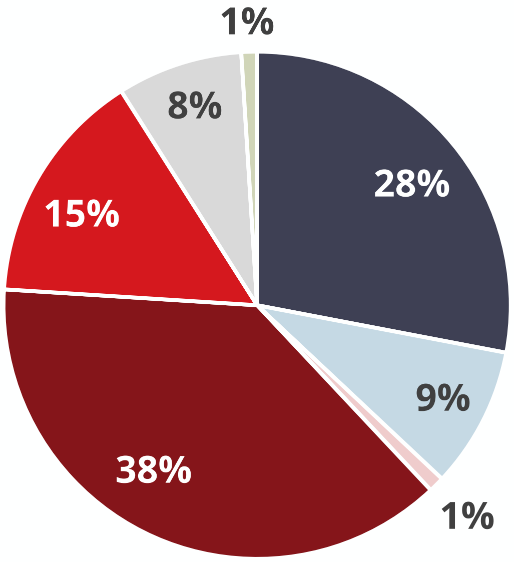
- ➢ Relationship Status



- Married/Partnered
- Divorced/Separated/Marriage annulled
- Single, never married
- Dating/In a serious relationship
- Widowed
- Other
- Not reported

- ➢ Employment Status



- Full time (≥30 hours/week)
- Part time (<30 hours/week)
- Temporary employment
- Not employed, retired
- Not employed, disability
- Not employed, student or other
- Prefer not to share

n = 3668

Participant Background

Sociodemographic Characteristics

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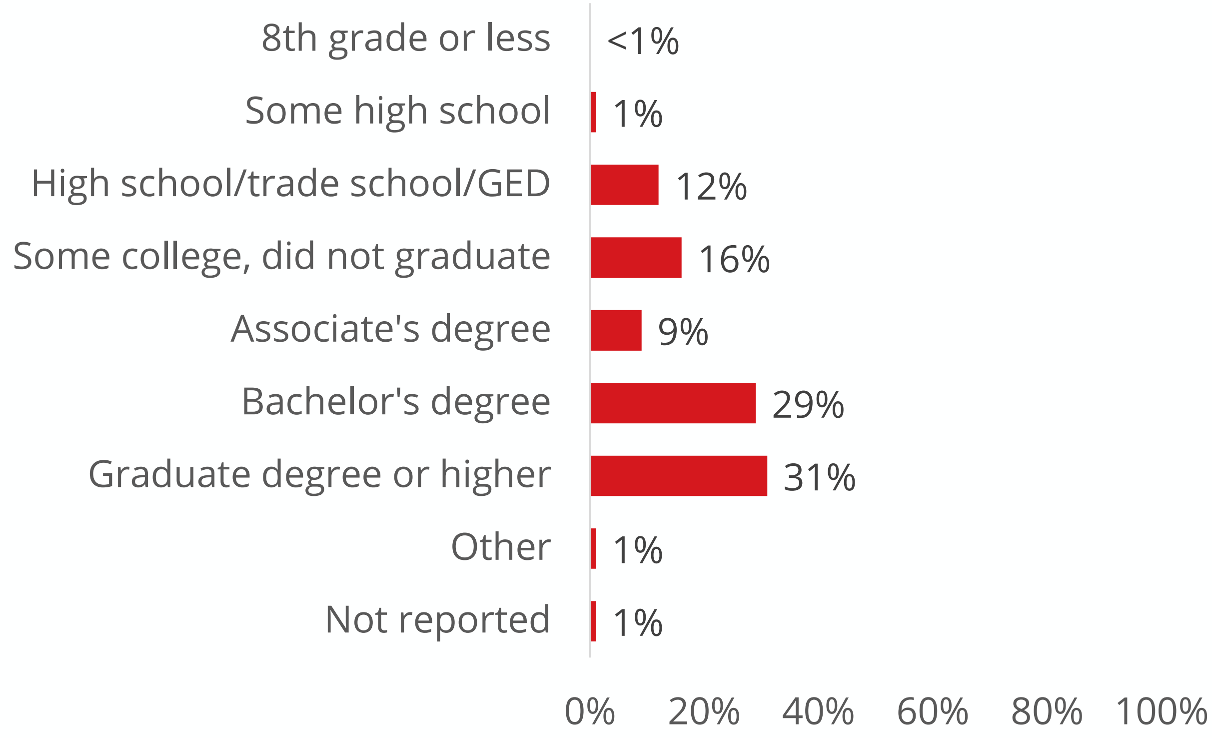
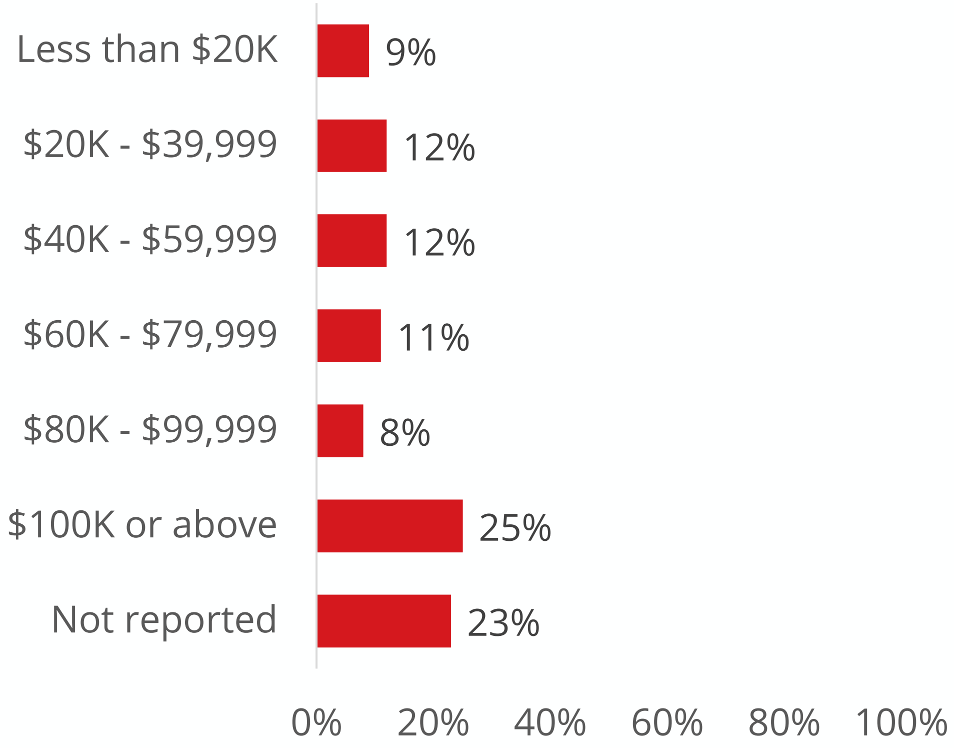
- Educational Attainment



- Annual Household Income

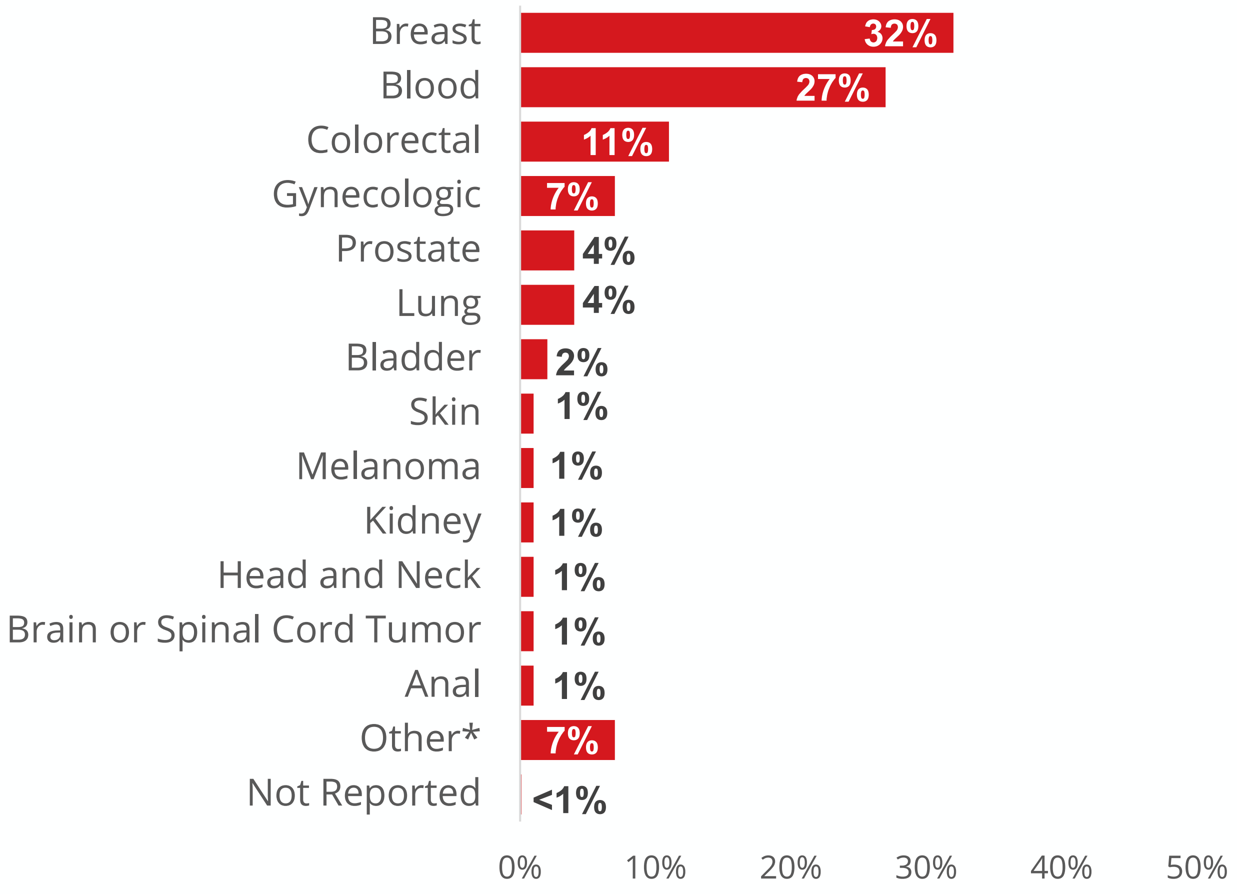


n = 3668

Participant Background

Clinical History

- Cancer Diagnosis



- Time Since Diagnosis
  - Mean: 6.2 (SD = 7.2)

	n	%
<1 year	306	8%
1-2 years	1169	30%
3-5 years	910	24%
6-10 years	703	18%
>10 years	710	19%

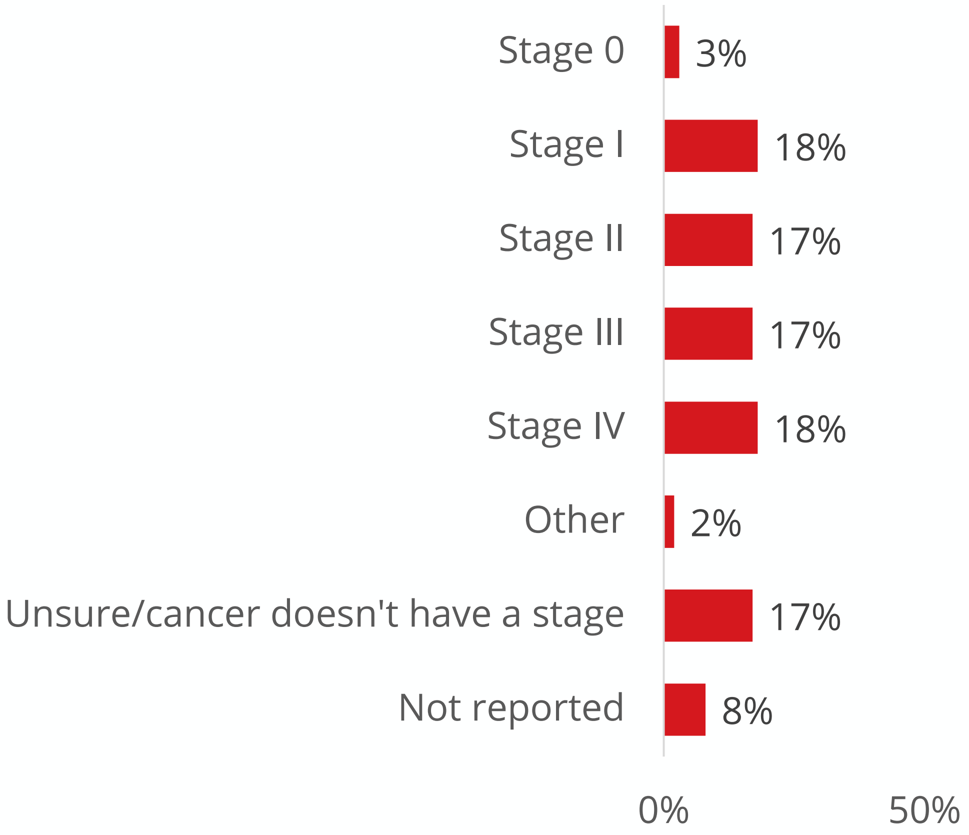
n = 3668

**Includes adrenal, bone, thyroid, testicular, esophageal, pancreatic, and other cancer types*

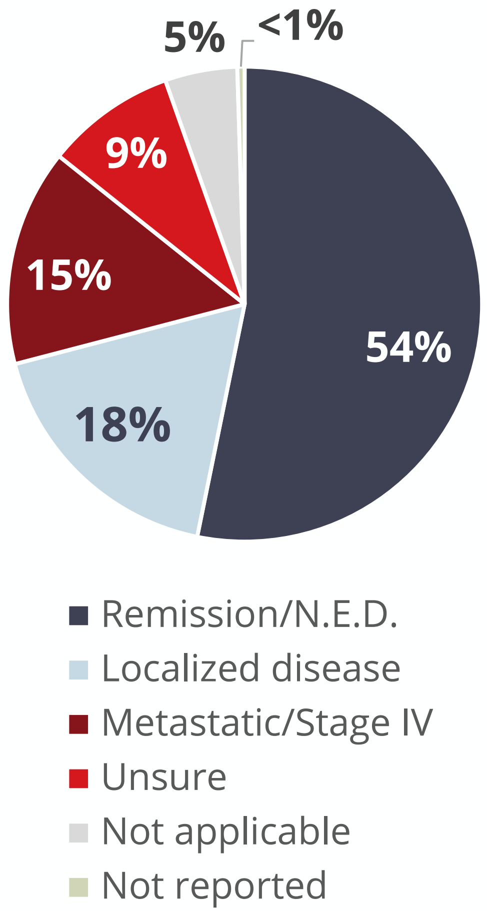
Participant Background

Clinical History

- Stage at Diagnosis



- Current Cancer Status

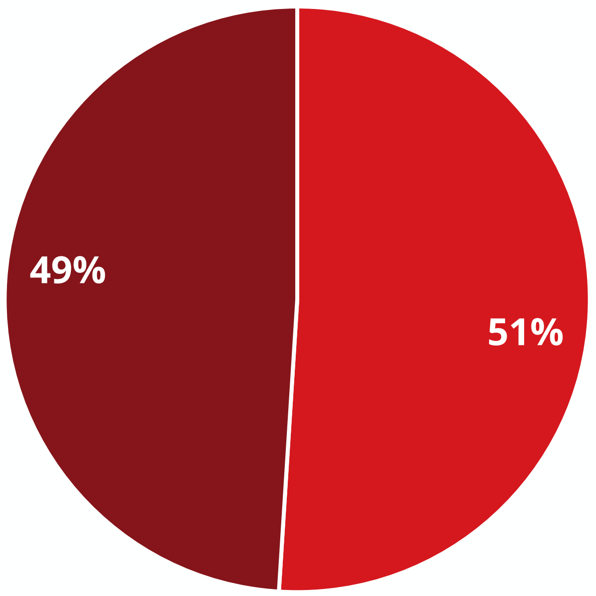


n = 3668

Participant Background

Clinical History

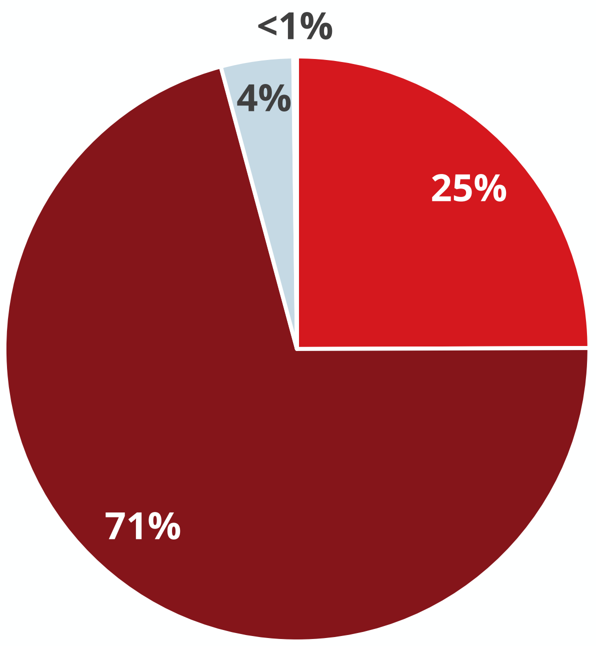
- ➢ Currently Receiving Treatment



n = 2713

🟥 Yes 🟥 No

- ➢ History of Cancer Recurrence



n = 3668

🟥 Yes 🟥 No ⬜ Unsure ⬛ Not reported

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III. Quality of Life

Quality of Life

Interpreting the PROMIS-29+2: Symptom Burden

Self-reported symptoms and functioning is measured using the Patient-Reported Outcomes Measurement Information System-29 (v2.0). Participants' scores are standardized to a metric that has been normed to the general U.S. population. For each domain, the general U.S. population mean is 50 (*Standard Deviation* = 10). Clinically meaningful differences have been defined as a 3-point difference in scores.

Five domains assess symptoms:

1. Anxiety
2. Depression
3. Fatigue
4. Pain Interference
5. Sleep Disturbance

Participants rate each symptom item with reference to the past 7 days. Higher scores correspond to worse symptomology; a mean >50 indicates worse symptomology, on average, than the general U.S. population.

Quality of Life

PROMIS-29+2 Symptom Burden

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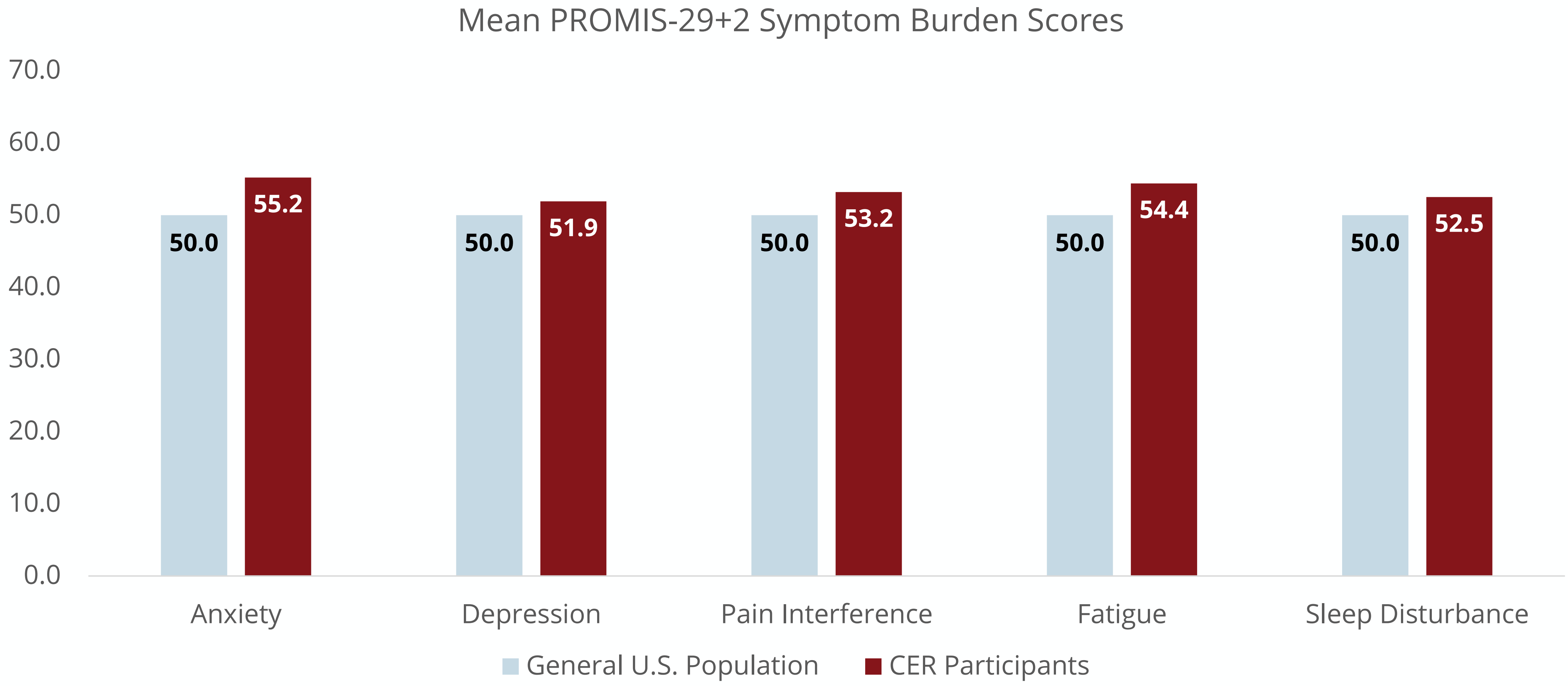


n = 3626-3644‡

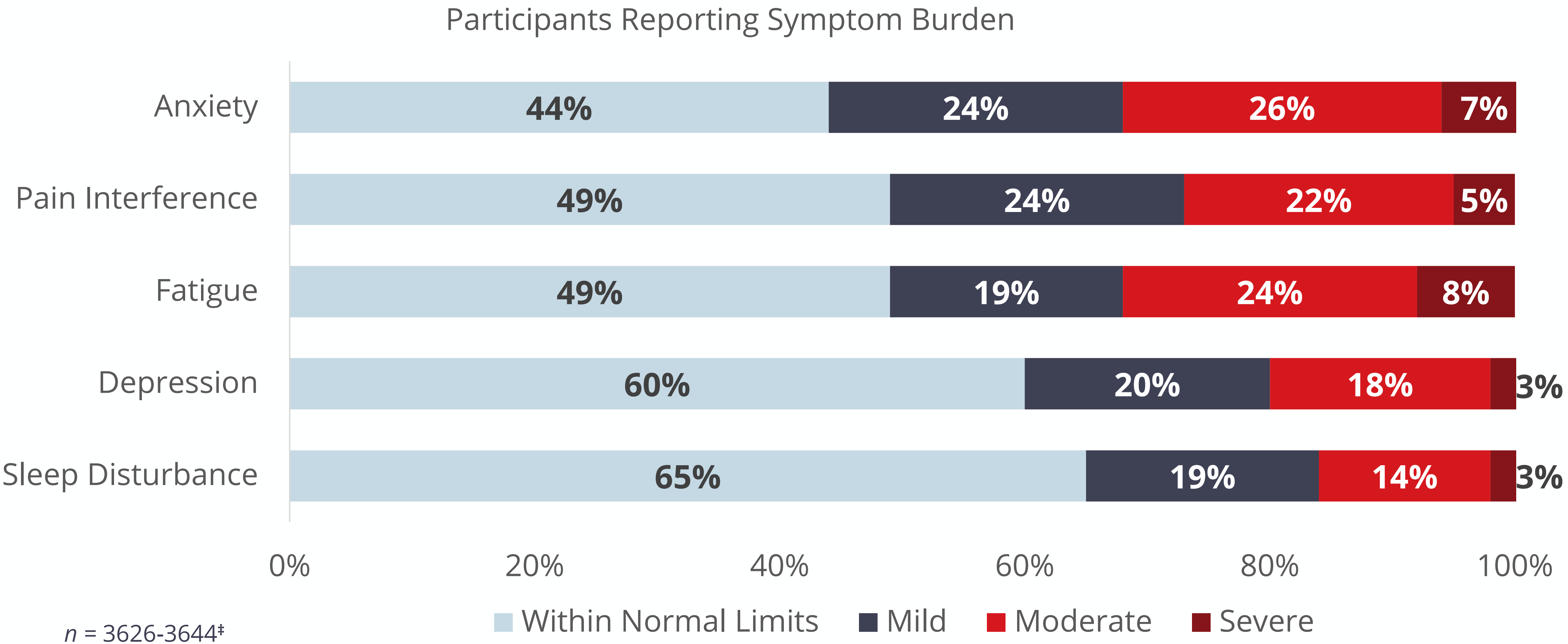
Note. 3-point differences are considered clinically meaningful

‡ PROMIS-29+2 requires complete data to allow for scoring

Quality of Life

PROMIS-29+2 Symptom Burden

CANCER SUPPORT COMMUNITY
CANCER EXPERIENCE REGISTRY



n = 3626-3644‡

Note. 15% of the general US population are categorized as moderate-severe using PROMIS benchmarks

‡ PROMIS-29+2 requires complete data to allow for scoring

Quality of Life

Interpreting the PROMIS-29+2: Function

Self-reported symptoms and functioning is measured using the Patient-Reported Outcomes Measurement Information System-29+2. Participants' scores are standardized to a metric that has been normed to the general U.S. population. For each domain, the general U.S. population mean is 50 (*Standard Deviation* = 10). Clinically meaningful differences have been defined as a 3-point difference in scores.

Three domains assess function:

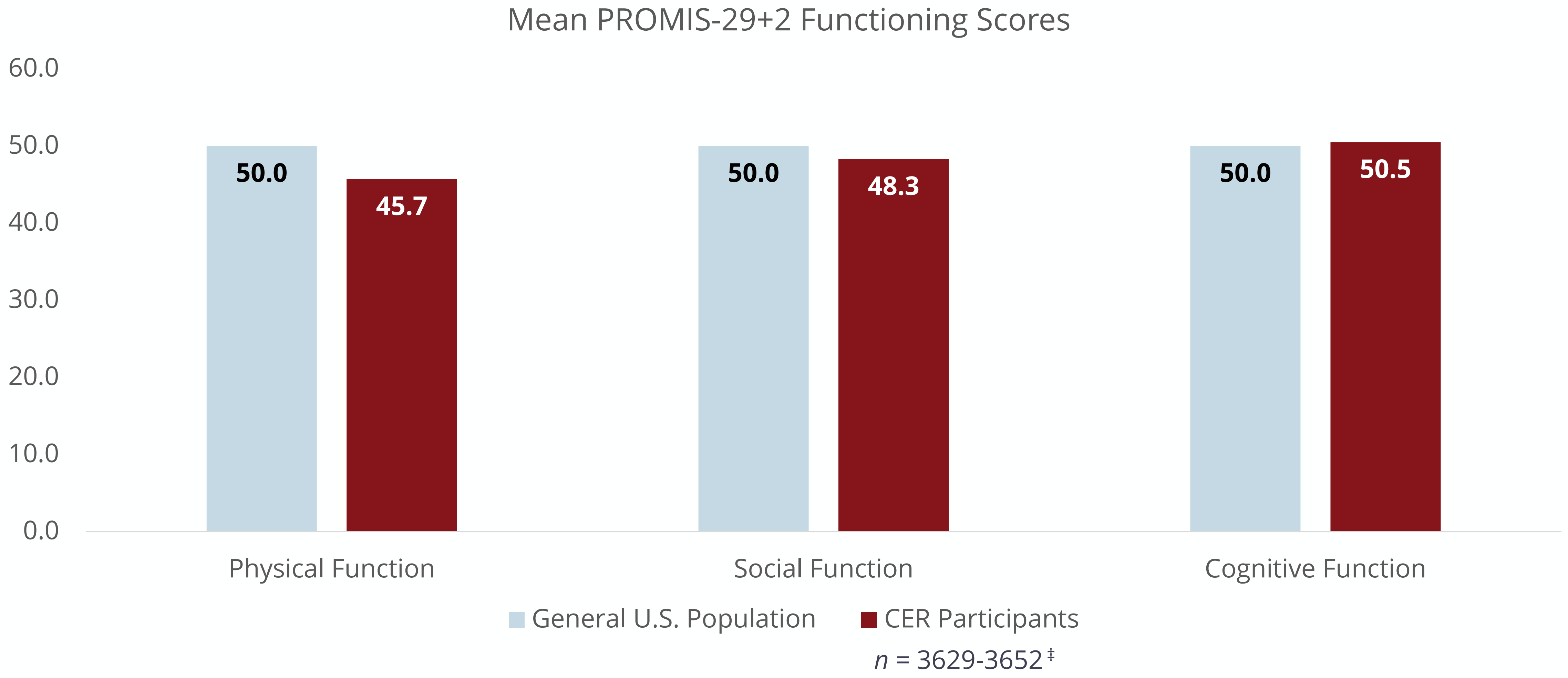
1. Physical Function
2. Social Function (Ability to Participate in Social Roles and Activities)
3. Cognitive Function

Function scales have no timeframe specified. Lower scores correspond to worse functioning; a mean <50 indicates worse functioning, on average, than the general U.S. population.

Quality of Life

PROMIS-29+2 Functioning

CANCER SUPPORT COMMUNITY
CANCER EXPERIENCE REGISTRY



Note. 3-point differences are considered clinically meaningful

‡ PROMIS-29+2 requires complete data to allow for scoring

Quality of Life

PROMIS-29+2 Functioning

CANCER SUPPORT COMMUNITY
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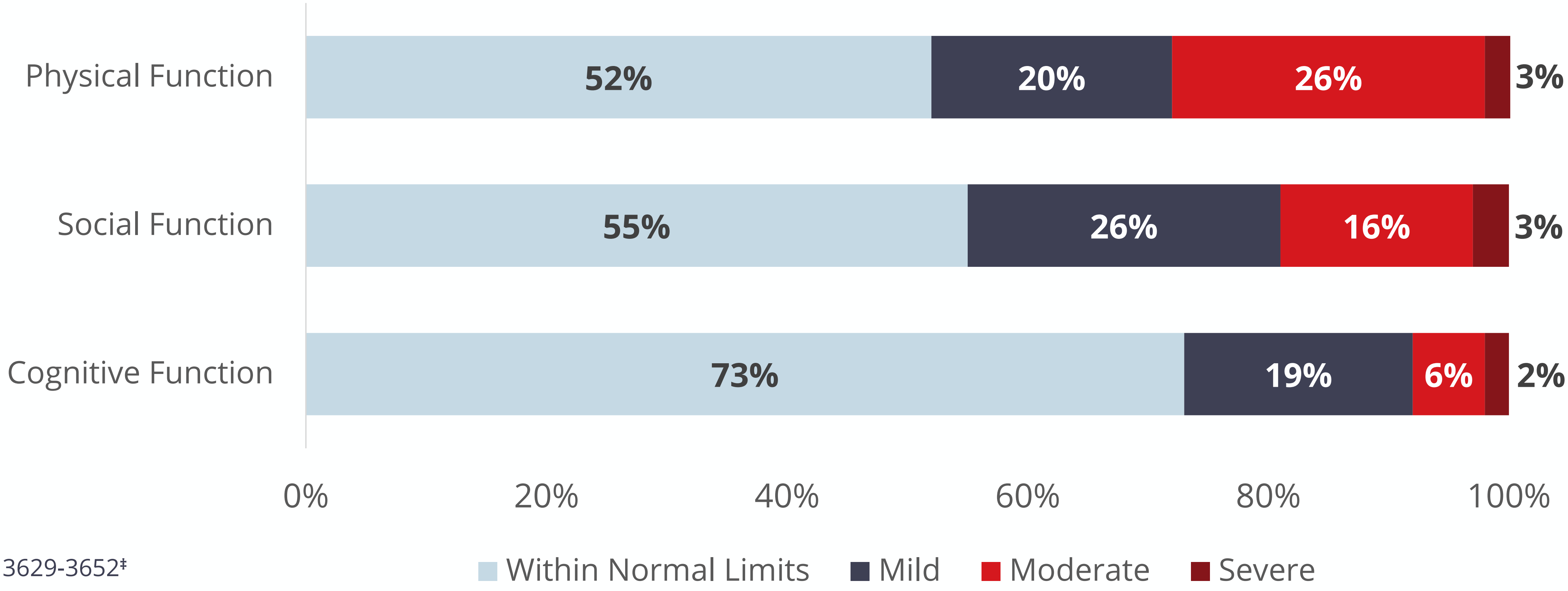
Participants Reporting Functional Impairment



n = 3629-3652‡

Note. 15% of the general US population are categorized as moderate-severe using PROMIS benchmarks

‡ PROMIS-29+2 requires complete data to allow for scoring

Quality of Life

CancerSupportSource

Self-reported cancer-related distress is measured using CancerSupportSource (CSS-25) plus 3 additional items.

Each question begins by asking, “Today, how concerned are you about…” and all 28 items are rated on a 5-point scale:

0 = Not all concerned
1 = Slightly concerned
2 = Moderately concerned
3 = Seriously concerned
4 = Very seriously concerned

The 10 items that participants most frequently rated as moderately, seriously, or very seriously concerned are categorized as Top 10 Concerns (shown on the following page).

These top-ranked concerns reveal areas of critical unmet need for this sample.

The complete list of items is shown at the end of the report.

Quality of Life

Top 10 Concerns – CancerSupportSource

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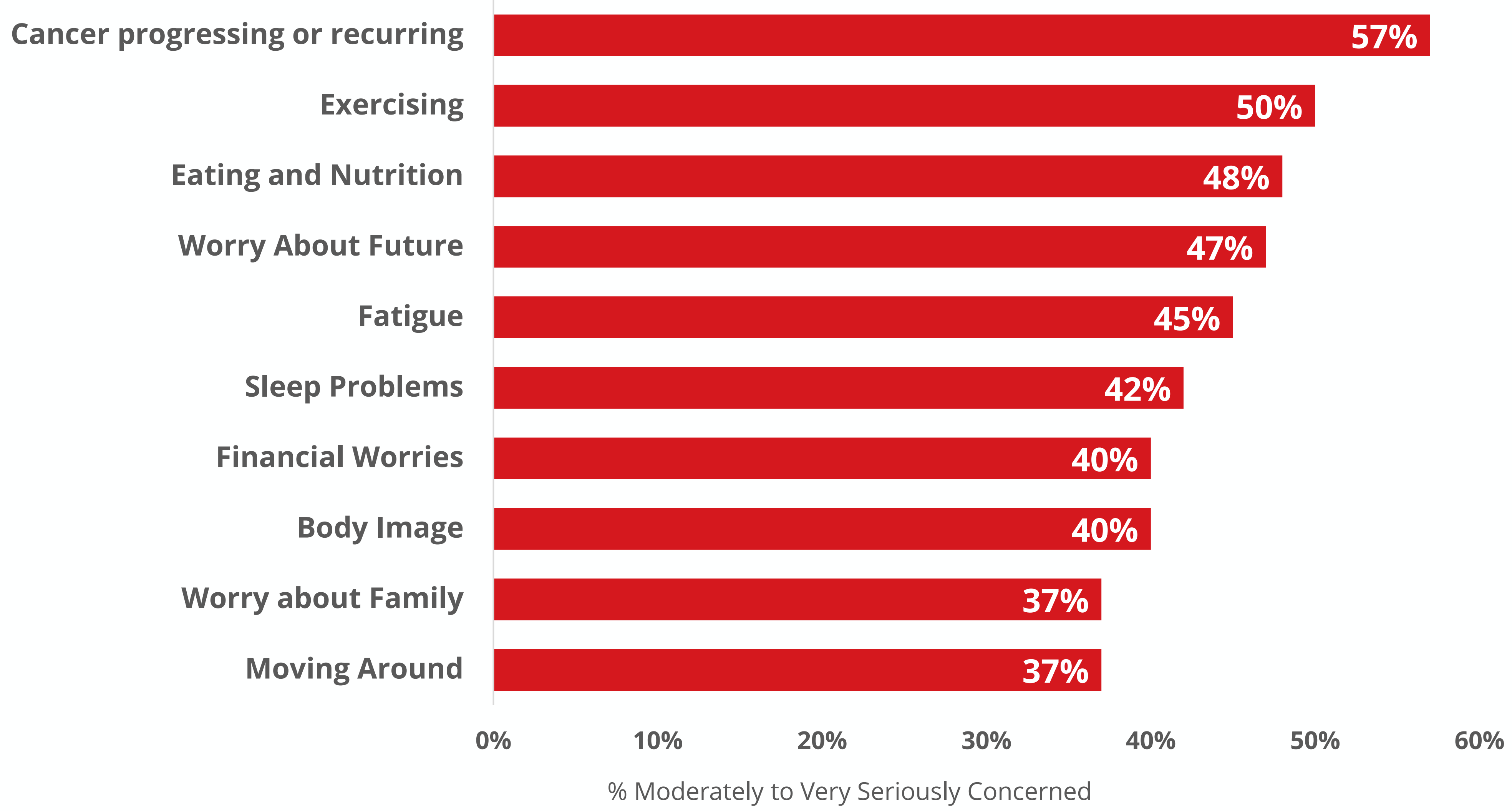


n = 3572-3628

Financial Toxicity

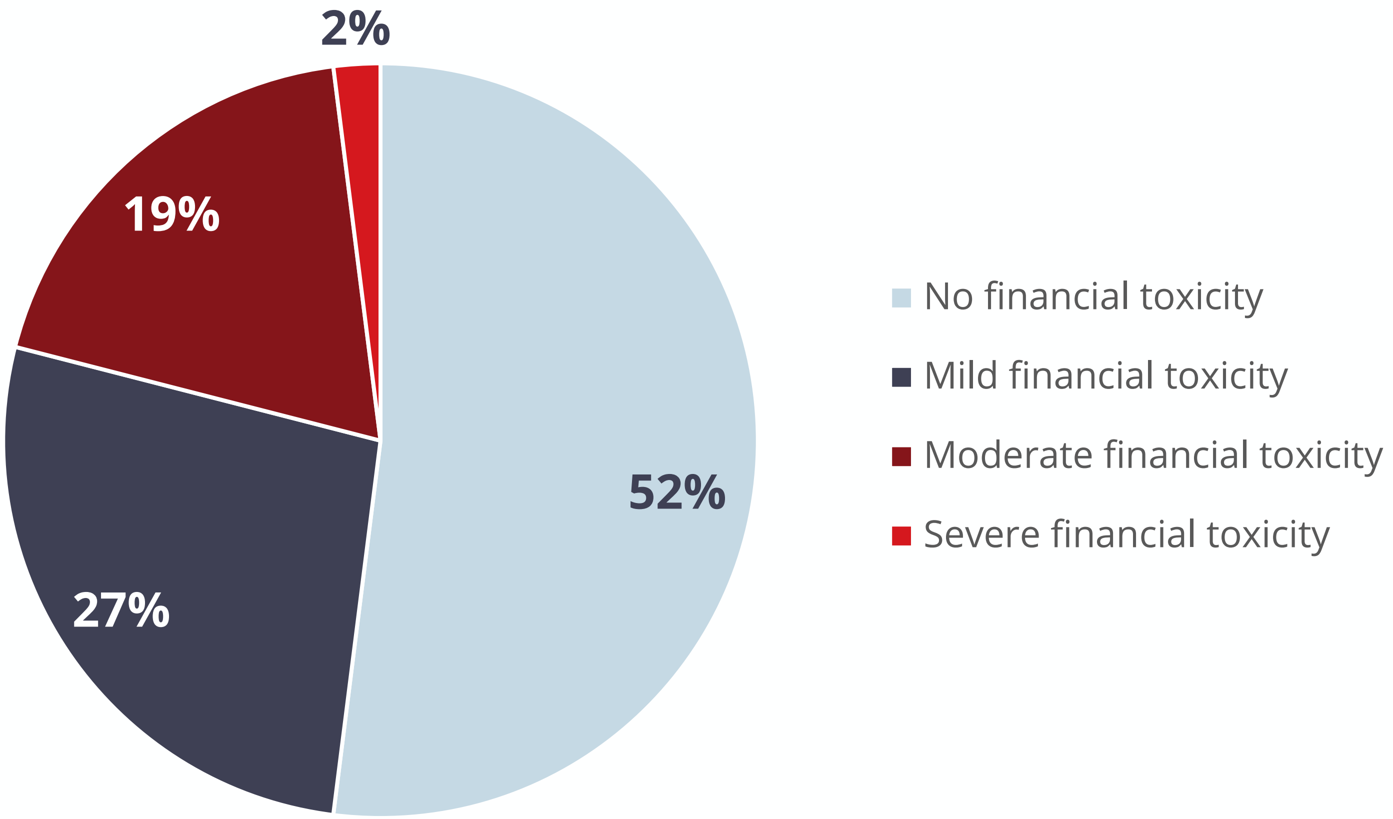
- Refers to the **objective monetary burden** and **subjective psychological distress** that cancer patients face as a result of their care
- Characterized by **out-of-pocket costs, lost productivity,** and **debt**
- Can lead to **negative clinical outcomes** (i.e., treatment adherence, **poor health**, and **poor quality of life**)
- Measured using the Comprehensive Score for financial Toxicity (COST) questionnaire

Financial toxicity is now considered to be ***"a side effect of cancer treatment"***

Quality of Life

Financial Toxicity

- **48%** of participants indicated at least mild levels of financial toxicity
- **21%** reported high (moderate to severe) financial toxicity
- **39%** did not feel knowledgeable at all about the financial impact of cancer treatment options available to them



n = 2170-3646

Quality of Life

Financial Impact

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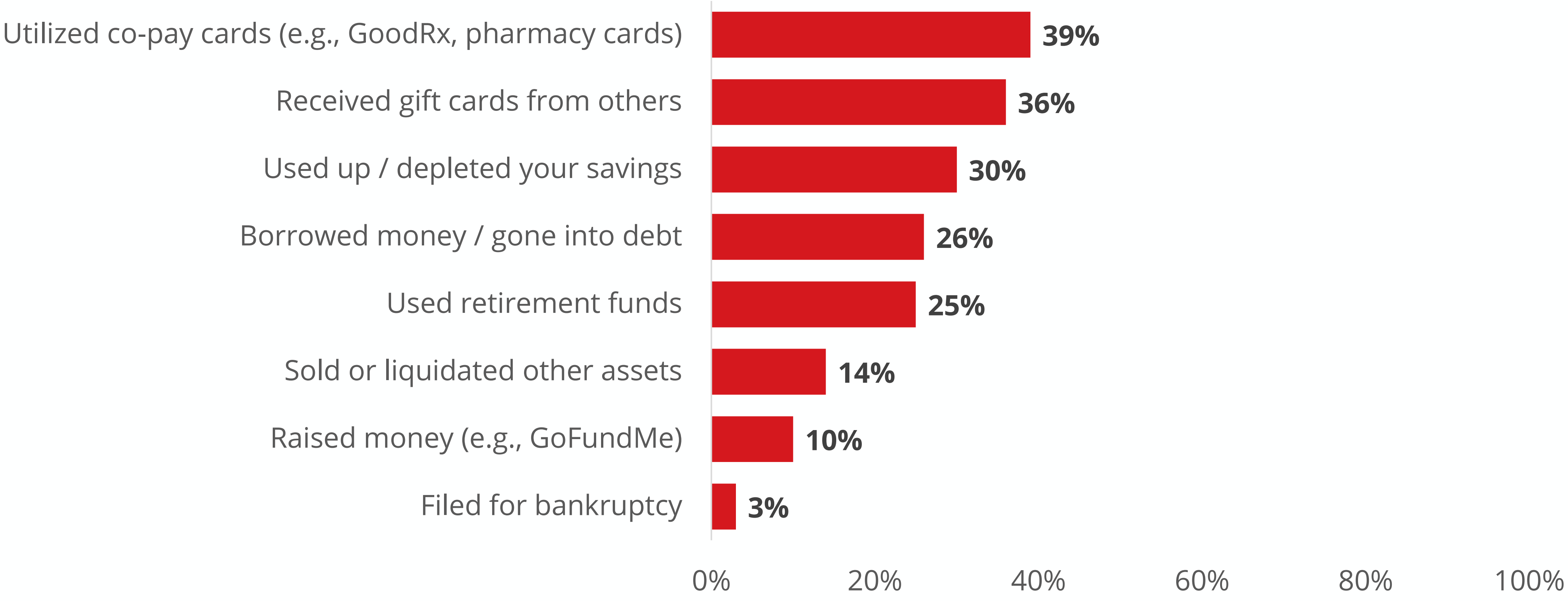
- Actions taken to manage costs related to cancer



n = 3423-3509

IV. Caregiver Support

Caregiver Support

81% of respondents had a caregiver (family or friend)

CER patient participants are asked if they wanted help from their caregivers for many tasks and support needs. They may respond to each task or support need by saying that they **wanted and did receive help**, **did not want help**, or **wanted and did not receive help**. Tasks or support needs for which patients wanted, but did not receive, help are referred to as **unmet needs,** while tasks for which patients wanted and did receive help are **met needs**.

Top 3 Unmet Needs:

Emotional support (13%)

Finding financial resources (12%)

Figuring out care and support roles (10%)

Top 3 Met Needs:

Transportation (82%)

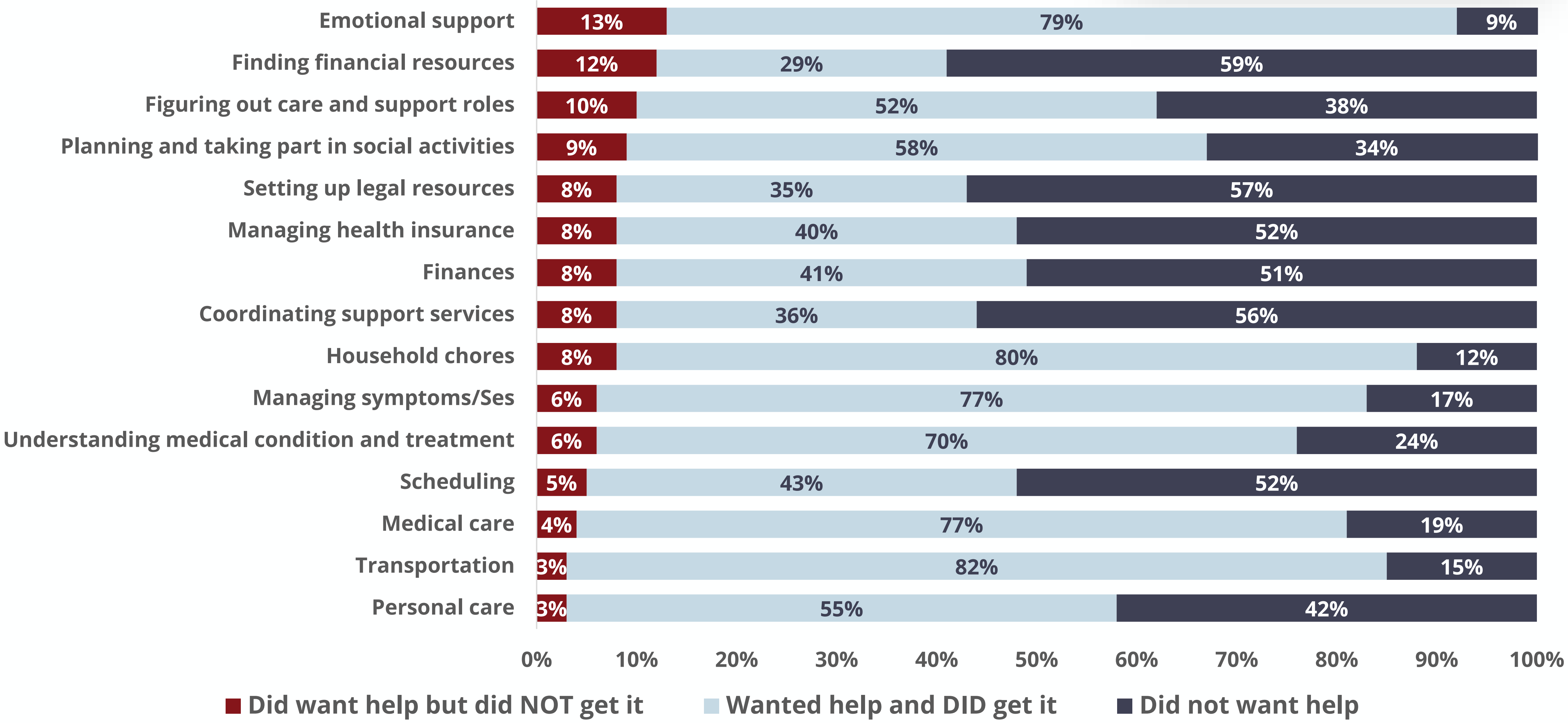
Household chores (80%)

Emotional support (79%)

Caregiver Support Needs

Top Needs of Patients Unmet by Caregivers

CANCER SUPPORT COMMUNITY
CANCER EXPERIENCE REGISTRY



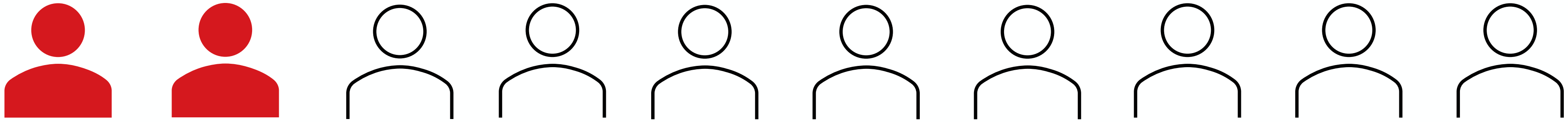
n = 2623-3526

V. Treatment Adherence

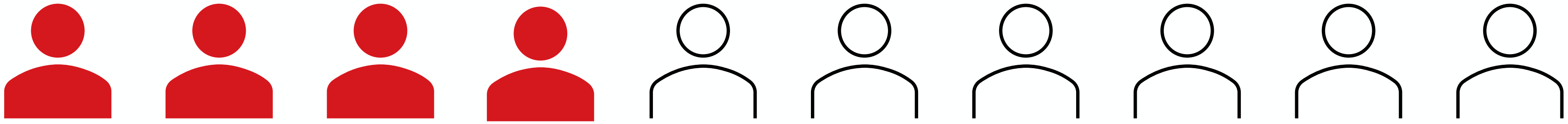
Treatment Adherence

Medication Adherence

- Participants taking prescription medication for their cancer (*n*=2055) responded to a set of questions regarding factors influencing their medication adherence. Of those:
  - 11% had a hard time remembering to take their medication
  - Nearly **2 in 10** indicated that taking their medication interfered with their daily schedule



  - Nearly **4 in 10** indicated that taking their medication was difficult because it caused side effects



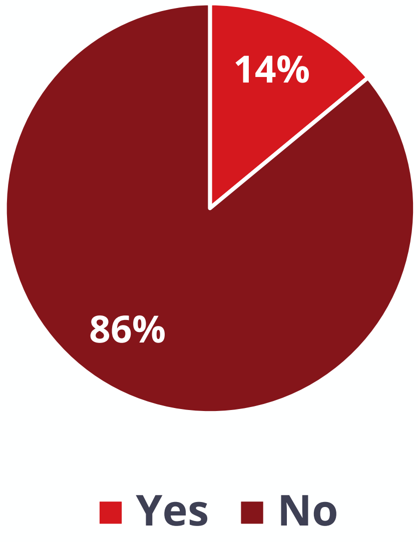
n = 1490-2055 participants who took prescription medication in the 12 months prior to completing the CER

Treatment Adherence

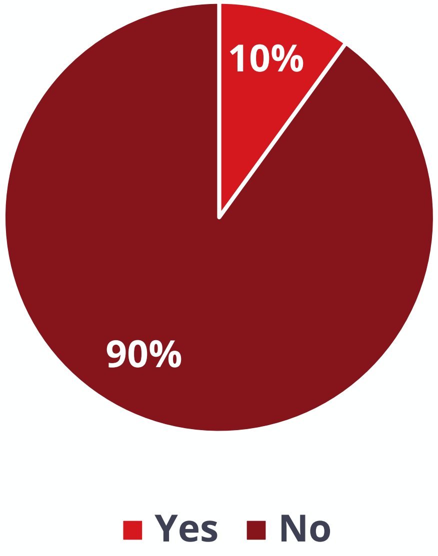
Financial Barriers

Of participants taking prescription medication for their cancer:

14% reported their medication cost too much to take it regularly



10% engaged in medication scrimping*



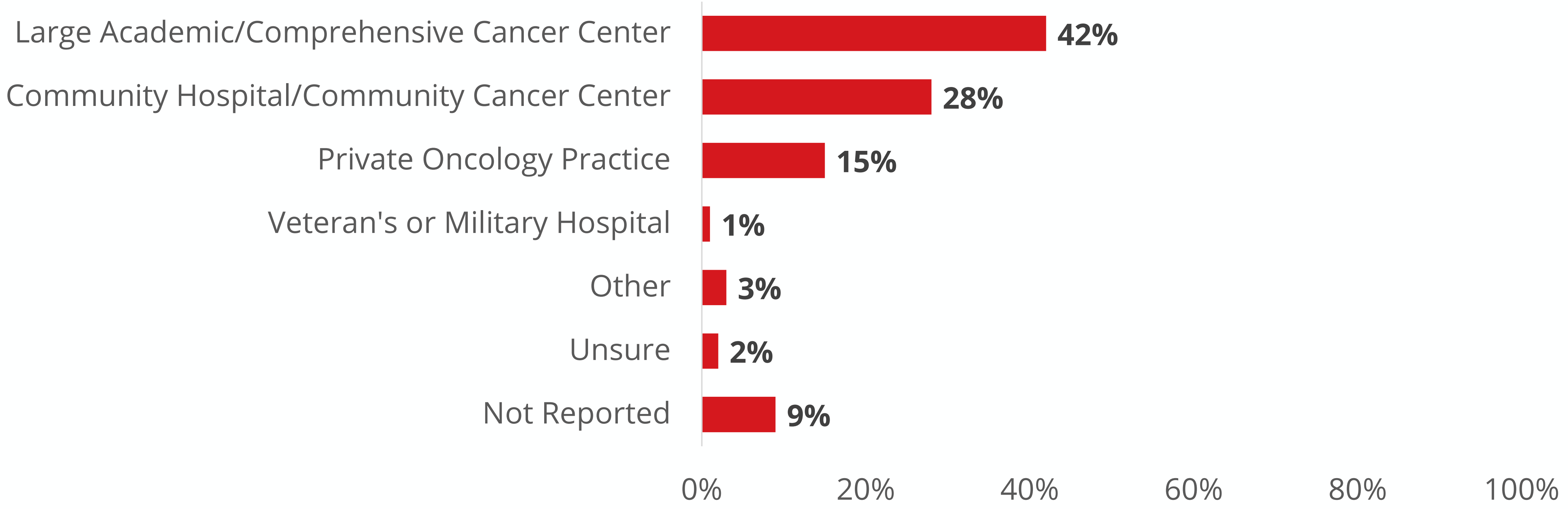
*skipping doses, taking less medication, or delaying refills to save money

VI. Access to Care

Access to Care

Care Delivery

- Participants receive(d) most of their cancer treatment in these settings:

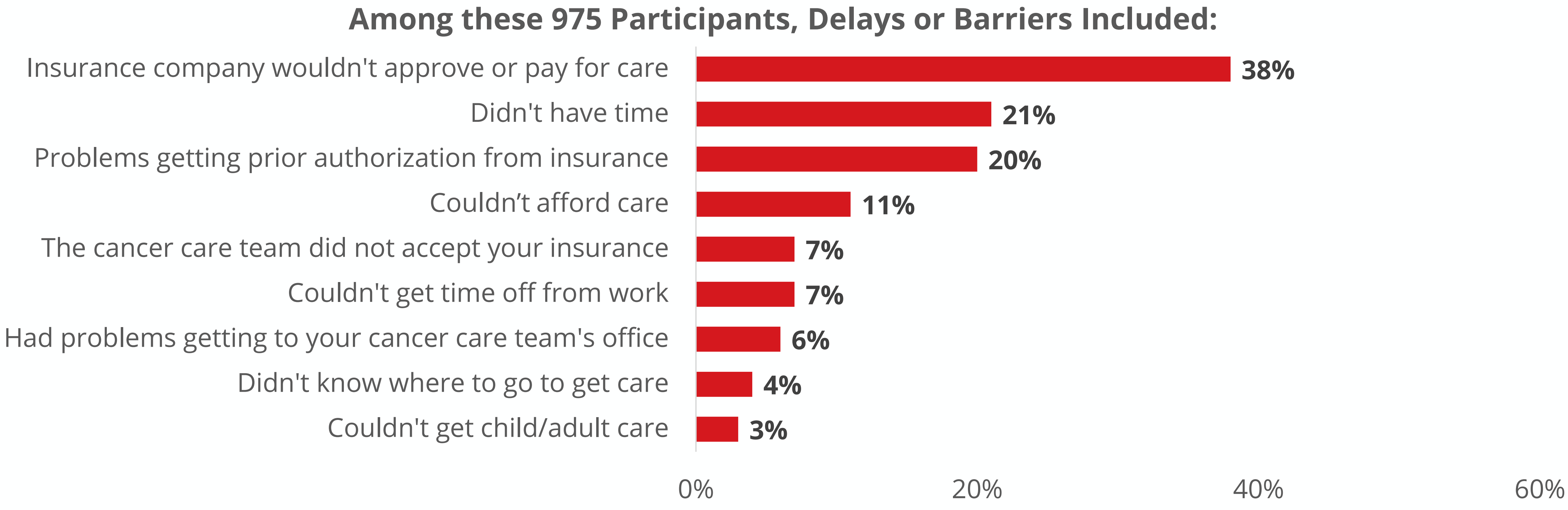


n = 3668

Access to Care

Facilitators & Barriers to Cancer Care

- 98% of participants reported having health insurance
- 975 of 3344 (29%) participants experienced delays or barriers to accessing cancer care or treatment at some point in their cancer experience.



Access to Care

Cancer Clinical Trials

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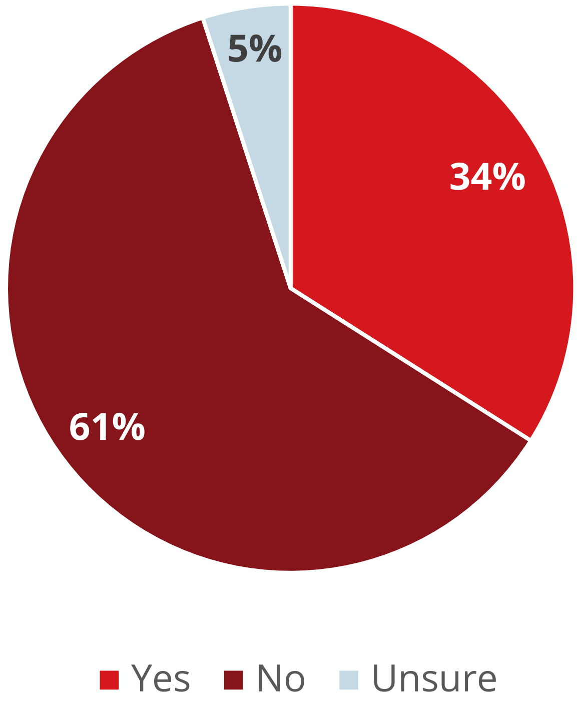
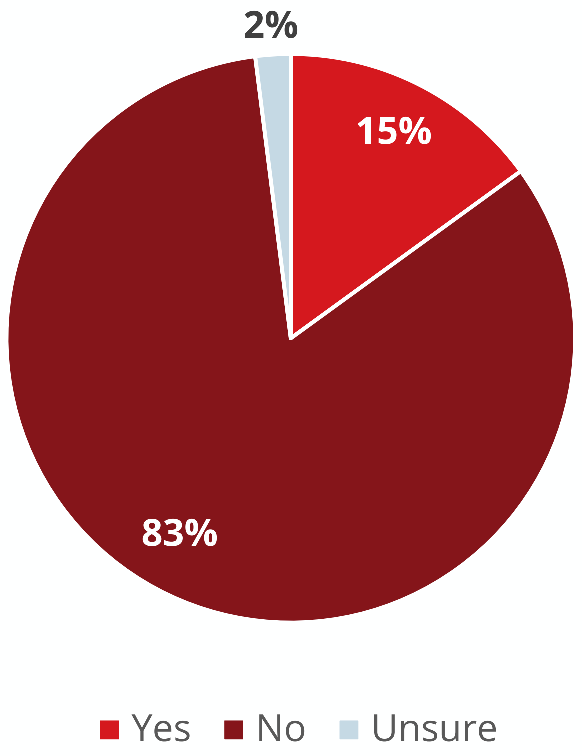
- Did a member of your cancer care team speak to you about clinical trials for cancer?



- Have you ever participated in a clinical trial for treatment of your cancer?



n = 3339-3340

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CANCER EXPERIENCE REGISTRY

VII. Health Behaviors

Health Behaviors

Comparisons to Public Health Guidelines

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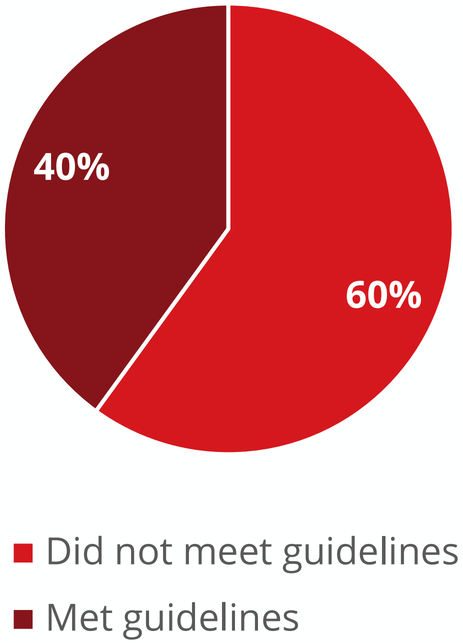
➢ Alcohol Consumption

- 60% (*n*=1964) reported not consuming alcohol in the prior 30 days
- Among those who did report drinking alcohol (*n*=1335)
  - On average, they consumed about 4 drinks per week
  - **88%** were *within guidelines for daily alcohol consumption*
    - Females: ≤1 drinks/day
    - Males: ≤2 drinks/day

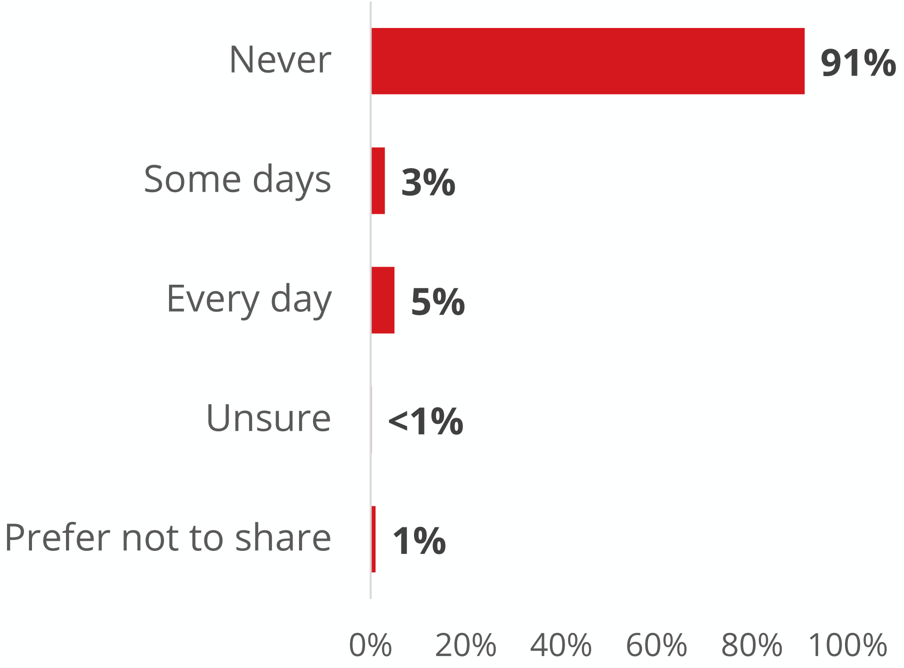
➢ Physical Activity

150+ Minutes/Week of Moderate Physical Activity



➢ Tobacco Use

Current Use of Tobacco Products*



*Cigarettes, chewing tobacco, e-cigarettes, etc.

n = 3301-3304

Health Behaviors

Interest in Wellness Strategies

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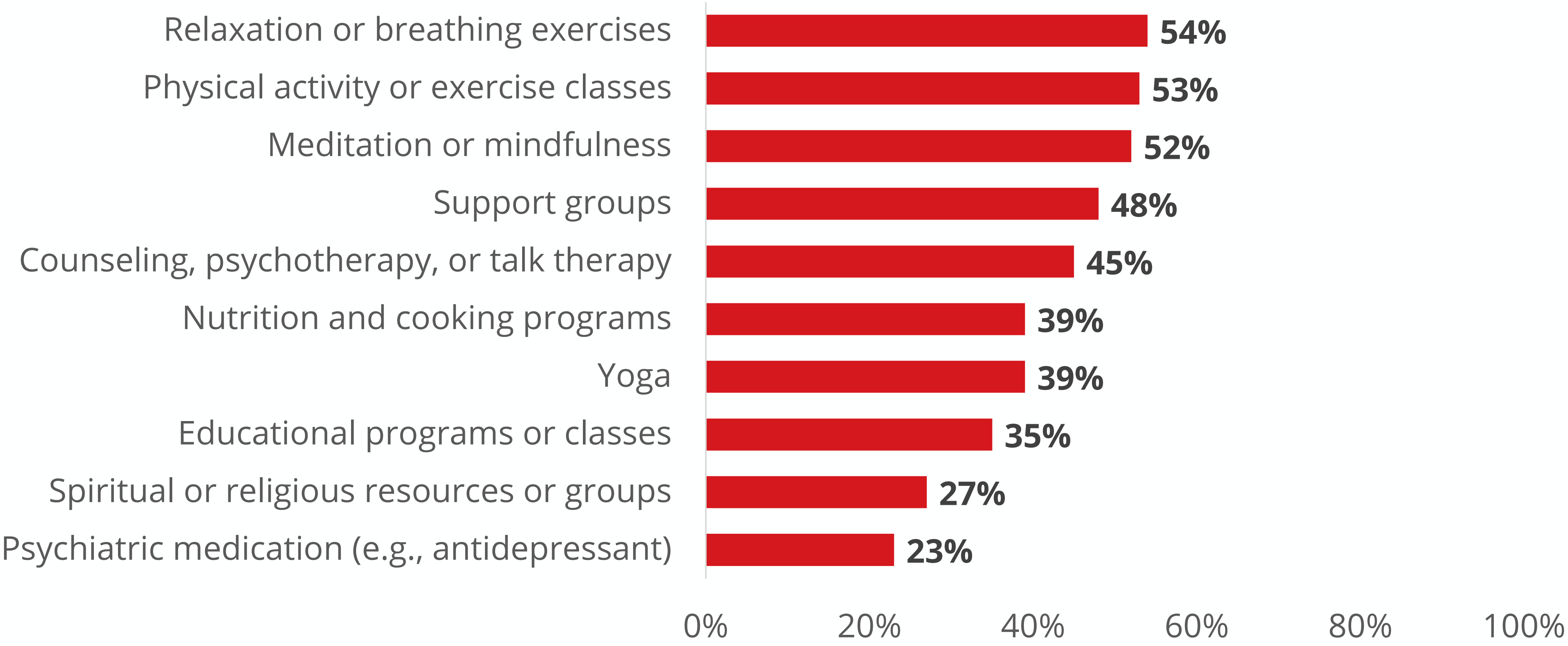
- Participant interest in health and wellness activities:



n = 3292

VIII. Patient Quotes

What Patients Say

How would you describe your overall cancer experience?

“Although it was one of the toughest 10 months of treatment, I am thankful for each day that I remain no evidence of disease. I am especially grateful for my wonderful cancer team for providing excellent care to assist me in fighting my cancer.”

“Confusing and highly stressful. Needing to make high-stakes decisions with limited knowledge and guidance while facing a life-threatening illness.”

“Early diagnosis and prompt care gave me a good outcome. I was treated well during all aspects and my questions/concerns were addressed. If it's possible to have a ‘good’ cancer experience I would say that would be mine.”

“Very hard to adjust to in the beginning , frightening and accepting a new change to my life from cancer care.”

What Patients Say

What have you learned during your experience with cancer that you wish you had known in the beginning?

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“A cancer diagnosis does NOT mean you are going to die from cancer. I learned that while I had a diagnosis, I also learned that I had OPTIONS, and for that I am so grateful!”

“Get a second opinion if you are uncomfortable with your oncologist and make a change right away when you are not receiving proper care.”

“Not to look too far ahead. Take the disease and treatment one step at a time.”

“Patients need to advocate for themselves. There isn’t ‘one’ decision to be made.”

“People are willing to help with things like cooking, cleaning, financial and emotional support.”

“Treatment is a moving target. What works for you might not work for me.”

“When you feel something isn’t right or no one is really listening to me, keep talking. Keep asking questions. Keep educating yourself. Be involved in your treatment.”

What Patients Say

Why did you decide to participate in this research study?

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“By sharing my experiences and insights, I can help researchers gather important data and gain a better understanding of various aspects of living with CLL.”

“Hopefully participating in surveys helps with more programs and community outreach for cancer patients.”

“I believe praise is free. As a retired deputy police chief, I was always on the lookout to catch my officers doing something good, and I would praise that performance. The Cancer Support Community organization does a wonderful job in helping people deal with the Big C diagnoses, and we all dread hearing ‘cancer.’ It sadly touches so many of us. So, anything I could do to support this work is something I would want to do.”

“I share my health/medical experiences with others to help prepare them, should they ever be in similar circumstances. I do a lot of research and preparation, and self-advocacy, but not everyone is interested in or capable of that. That doesn’t mean they don’t need information, so the easier it is to come by, the better. If something I’ve shared here is useful to another cancer patient somehow, that’s a win for me.”

IX. 2024 Presentations and Publications

Accessing Palliative and Supportive Care Providers Moderates Association between Concerns and Psychological Distress in Older Adults with Cancer

American Psychosocial Oncology Society Annual Conference 2024

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- **Aim**: Investigate the relationship between multidimensional concerns and anxiety and depression in older adults diagnosed with cancer in the past five years, exploring variability in these relationships by utilization of various interdisciplinary providers.

- **Main Findings**: Accessing interdisciplinary providers, such as palliative care providers, mental or behavioral health providers, physical or occupational therapists, and more, for assistance with symptoms and side effects in the past year significantly attenuates relationship between cancer-related concerns and symptoms of anxiety/depression among older adults with cancer.

Link to Poster

Professional Support for Eating and Nutrition among Women Living with Breast Cancer: Implications for Mental Health and Quality of Life

Oncology Nutrition Symposium 2024

- **Aim**: Describe the patient experience with professional support for eating and nutrition among women living with breast cancer and to explore the relationship between health-related quality of life and access to nutrition support

- **Main Findings**: While there is a strong desire for professional support surrounding eating and nutrition among women with breast cancer, when that support is needed and what it aims to address varies greatly. Among those interested in receiving professional support for eating and nutrition, those who accessed support reported greater mental health and quality of life.

Link to Poster

Patient-Centered Communication and Knowledge and Preparedness in Treatment Decision-Making among People with Lung Cancer

CANCER SUPPORT COMMUNITY
CANCER EXPERIENCE REGISTRY

World Conference on Lung Cancer 2024

- **Aim**: Examine the impact of patient-centered communication among people with lung cancer on knowledge and preparedness in treatment decision-making.

- **Main Findings**: Patient-centered communication was a significant predictor of greater knowledge and preparedness in treatment decision-making among people with lung cancer. Successful patient-provider communication influences treatment decisions among people with lung cancer.

Link to Presentation

Perceptions of treatment tolerability and its relationship to income in patients with hematologic malignancy: Findings from the Cancer Experience Registry

American Society of Hematology

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CANCER EXPERIENCE REGISTRY

- **Aim**: Further understand patients' perceptions of hematologic malignancy cancer treatment tolerability and investigate how these perceptions are related to income.

- **Main Findings**: Symptom relief, ability to slow disease progression, and treatment side effects were the top 3 aspects considered when determining treatment tolerability for all participants, regardless of income. These concerns are largely consistent across income groups, but findings suggest that those with lower income may prioritize treatment access factors, such as cost, location, and frequency of care more than those with higher income. Additionally, emotional well-being impacts were prioritized more by lower-income patients, highlighting the need for tailored support services.

Link to Poster

Treatment tolerability and adherence in people living with metastatic and non-metastatic breast cancer: Findings from the Cancer Experience Registry

San Antonio Breast Cancer Symposium

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CANCER EXPERIENCE REGISTRY

- **Aim**: Further understand breast cancer patients' perceptions of treatment tolerability by metastatic status and association with adherence.

- **Main Findings**: The three most important factors determining whether a treatment was tolerable were: ability to slow disease progression, symptom relief, and side effects of treatment. When looking at top factors by metastatic status, the top three remain unchanged for those who are metastatic. For those who are non-metastatic, potential cure was deemed more important than side effects. Non-adherence was specifically associated with some important factors related to treatment tolerability, including cost of treatment, treatment impact on daily life and emotional well-being.

Link to Poster

Financial toxicity among people with metastatic cancer: findings from the Cancer Experience Registry

Supportive Care in Cancer

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COMMUNITY
CANCER EXPERIENCE REGISTRY

- **Aim**: Describe financial toxicity reported by people with metastatic cancer, characteristics associated with financial toxicity, and associations between financial toxicity and compensatory strategies to offset costs.

- **Main Findings**: About half of participants reported some degree of financial toxicity. Individuals who reported financial toxicity were more likely to postpone medical visits, have suboptimal treatment adherence, and postpone supportive care and/or psychological support services.

Link to Manuscript

Survivorship concerns among individuals diagnosed with metastatic cancer: Findings from the Cancer Experience Registry

CANCER SUPPORT
COMMUNITY
CANCER EXPERIENCE REGISTRY

Journal of Cancer Survivorship

- **Aim**: Describe the type and prevalence of survivorship concerns reported by individuals with metastatic cancer, and their associations with cancer diagnosis, treatment, and socio-demographic variables.

- **Main Findings**: The most common survivorship concern was cancer progression or recurrence. Individuals who were unemployed due to disability reported higher concern among many domains. Survivorship concerns related to emotional well-being, symptom burden, and healthcare communication were higher among those within 5 years of diagnosis.

Link to Manuscript

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THANK YOU

CancerSupportCommunity.org/Registry

X. APPENDIX

Quality of Life

Cancer-Related Concerns

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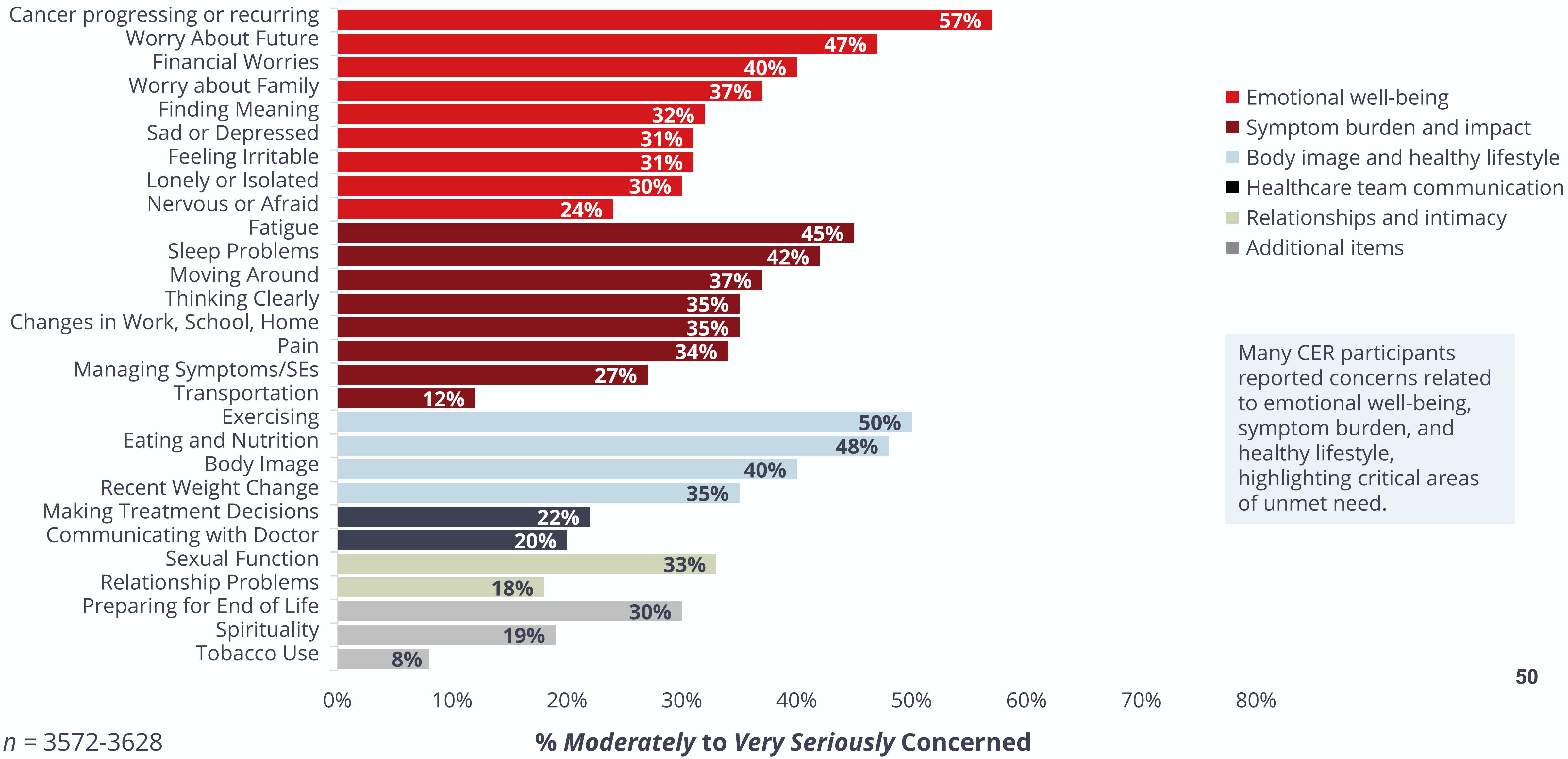


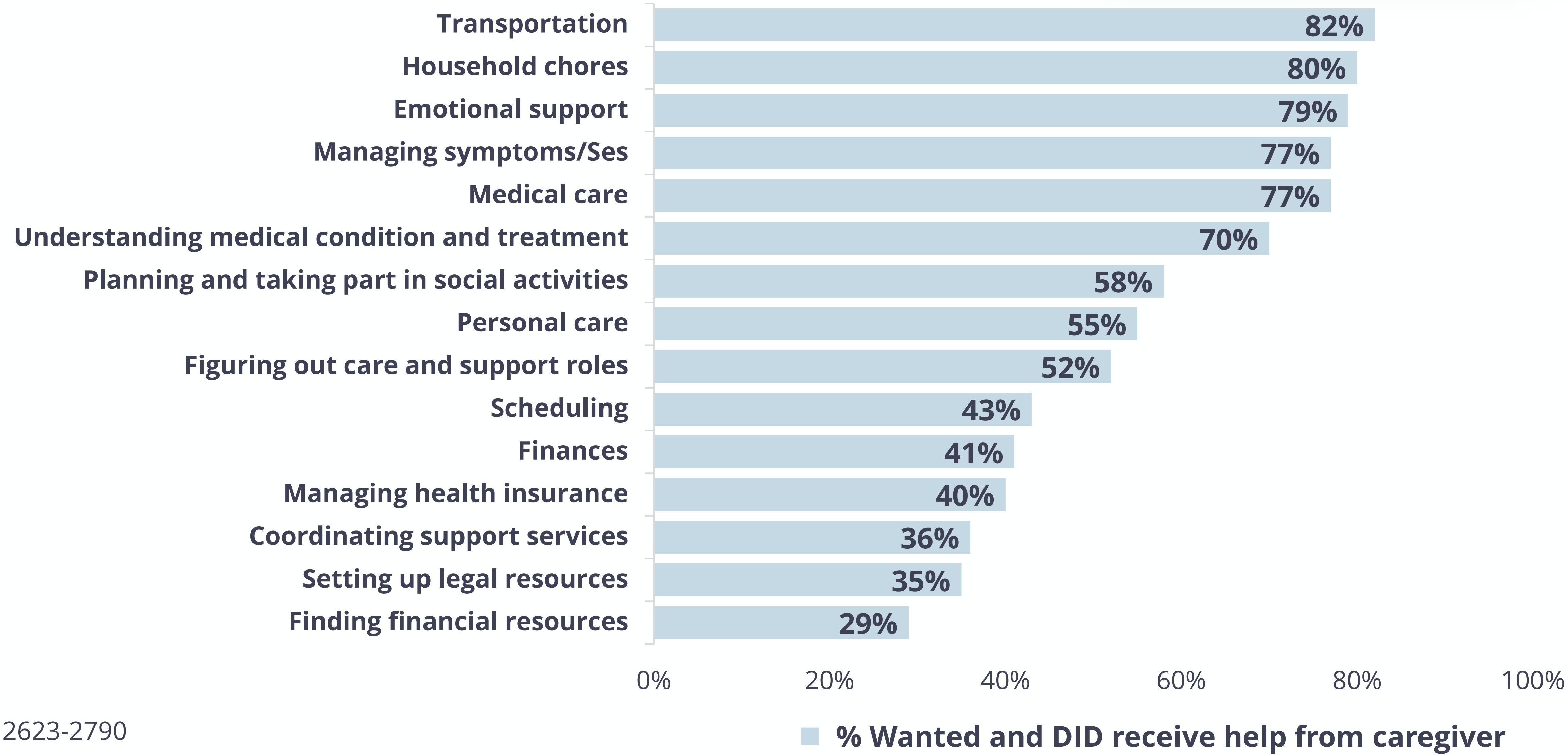
Many CER participants reported concerns related to emotional well-being, symptom burden, and healthy lifestyle, highlighting critical areas of unmet need.

n = 3572-3628

Caregiver Support Needs

Top Met Needs

CANCER SUPPORT COMMUNITY
CANCER EXPERIENCE REGISTRY



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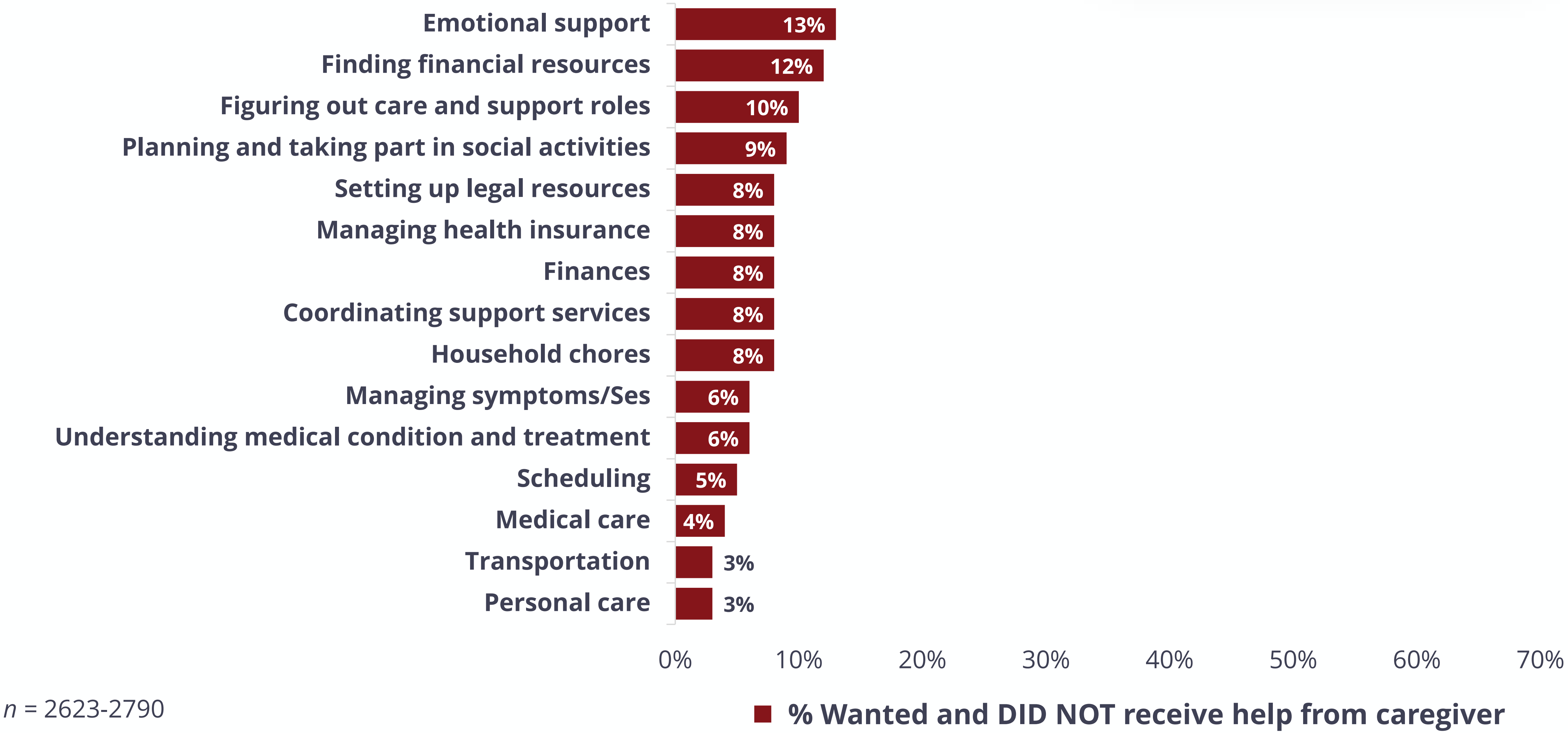
Caregiver Support Needs

Top Unmet Needs



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