Cancer Experience Registry: Results and Practice Implications

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Oncology Nutrition
a dietetic practice group of the
Academy of Nutrition and Dietetics

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S CLUB

Conflicts of Interest Disclosures

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Nutrition Services in Oncology: A Survey of Patient Experiences, Needs, and Gaps in Care

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Learning Objectives

By the end of this session, participants will be able to:

1. **Describe** patterns of nutrition care engagement among cancer survivors, including rates of RDN utilization and unmet need.
2. **Identify** sociodemographic and clinical factors associated with unmet nutrition care need, low perceived need, and uncertainty.
3. **Recognize** critical time points in the cancer care continuum (treatment and post-treatment) when nutrition service demand is highest.

Cancer Support Community

Our Mission

The Cancer Support Community uplifts and strengthens people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care.

Our Vision

Everyone impacted by cancer receives the support they want and need throughout their experience.

What We Do

Services, Insight, and Advocacy

OUR REACH: GLOBAL NETWORK PARTNERS

NATIONAL

CSC ARIZONA
CSC SOUTH BAY
CSC GREATER SAN GABRIEL VALLEY
CSC LOS ANGELES
CSC CALIFORNIA CENTRAL COAST
CSC SAN FRANCISCO BAY AREA
CSC VALLEY/VENTURA/SANTA BARBARA
CSC SW COLORADO
CSC DELAWARE
CSC WASHINGTON D.C.
GC SOUTH FLORIDA
CSC ATLANTA
GC CHICAGO
CSC INDIANA
CSC IOWA & NW ILLINOIS AT GILDA'S CLUB
GC KENTUCKIANA
CSC MASSACHUSETTS
CSC GREATER ANN ARBOR
GC GRAND RAPIDS
GC METRO DETROIT
GC MINNESOTA
CSC GREATER ST. LOUIS
GC KANSAS CITY
CSC MONTANA
CSC NEW JERSEY
CSC AT GILDA'S CLUB ROCHESTER
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CSC GREATER CINCINNATI-NORTHERN KENTUCKY
CSC CENTRAL OHIO
CSC GREATER LEHIGH VALLEY
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HEALTH CARE PARTNERS

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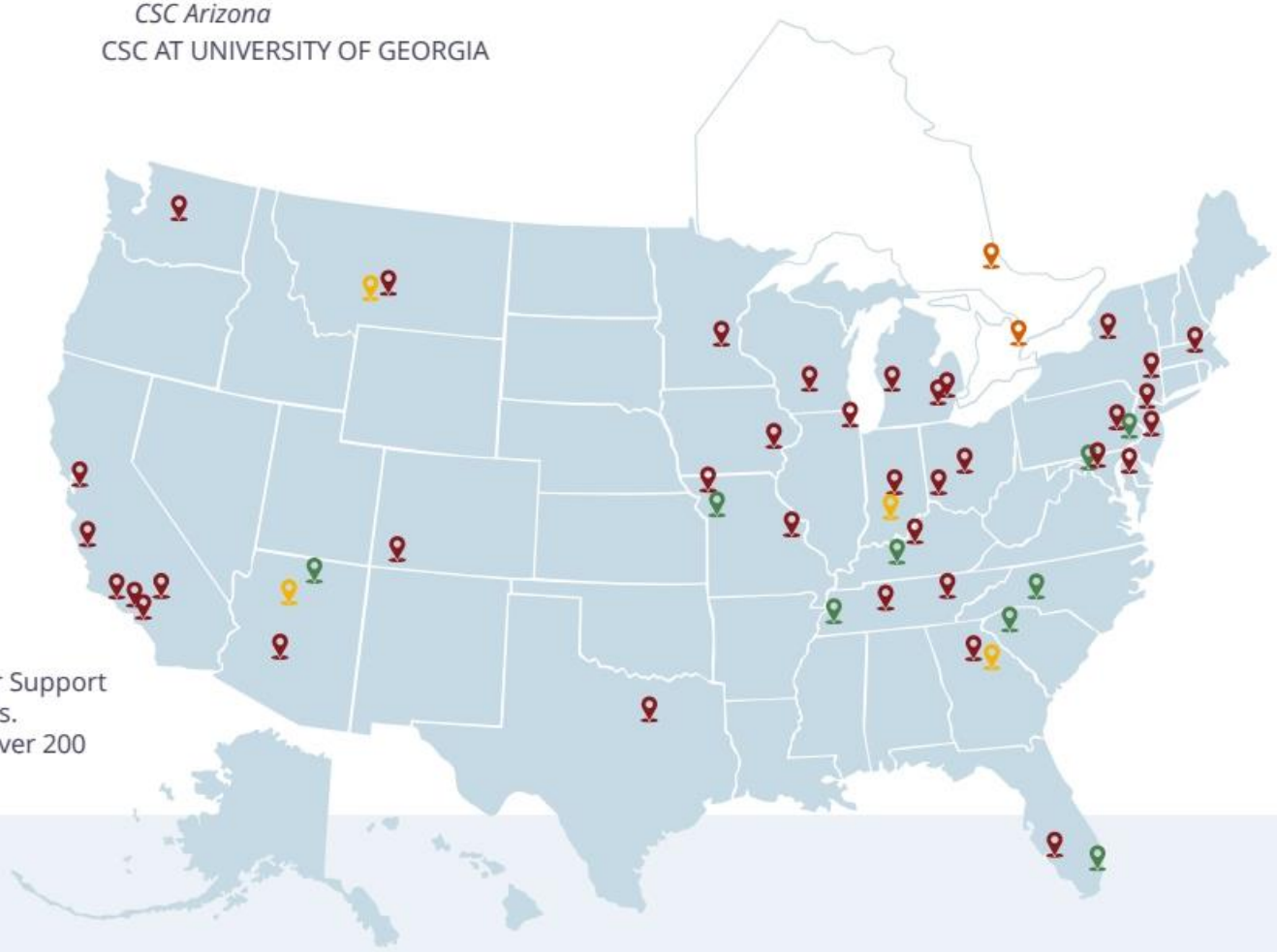
UNIVERSITY LOCATIONS

CSC AT INDIANA UNIVERSITY
CSC Indiana
CSC AT MONTANA STATE UNIVERSITY
CSC Montana
CSC AT NORTHERN ARIZONA UNIVERSITY
CSC Arizona
CSC AT UNIVERSITY OF GEORGIA

INTERNATIONAL

GC GREATER TORONTO
GC SIMCOE MUSKOKA
CSC BAGHDAD
CSC JAPAN
TWC TEL-AVIV

HUB AND SPOKE MODEL:
The map shows all the North America Cancer Support Community (CSC)/Gilda's Club (GC) main hubs. Following a hub and spoke model, we have over 200 locations in 50 markets worldwide.



CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S CLUB

CSC Research & Training Institute

As experts in capturing unmet needs of cancer patients and caregivers, we evaluate patient, survivor, and caregiver voices through **psychosocial, behavioral, financial, survivorship,** and **health economics and outcomes research** using **real-world non-clinical data** to:

- Understand the cancer experience and impact
- Enhance cancer care
- Guide program development
- Influence health-related policy

Cancer Experience Registry (CER)

An online research study that aims to understand the emotional, physical, practical, and financial impact of cancer and identify unmet needs among patients, survivors, and caregivers.

Cancer Experience Registry (CER)

What?

An online research study that uncovers the broad impact of cancer

Who?

For patients, survivors and caregivers aged 18+ impacted by **any type of cancer, regardless of time since diagnosis**

Where?

On your computer or mobile device from anywhere in the U.S. or Canada

Why?

To ensure all those impacted by cancer receive necessary support and resources

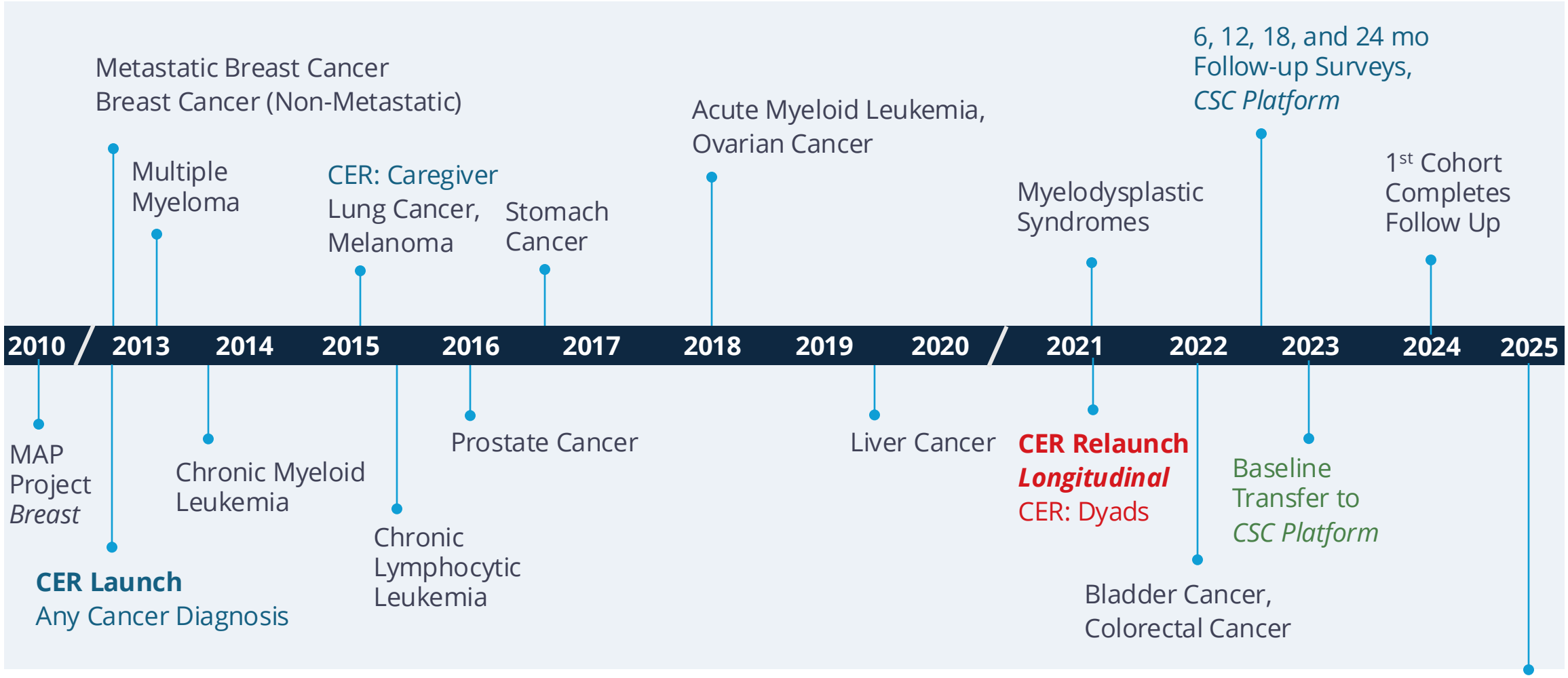
When?

- Baseline survey: 30 minutes
- Follow-up surveys: Four surveys sent every six months over two years

How?

Developed in collaboration with patients, survivors, caregivers, clinicians, advocacy organizations, social workers, researchers

CER Historical Timeline



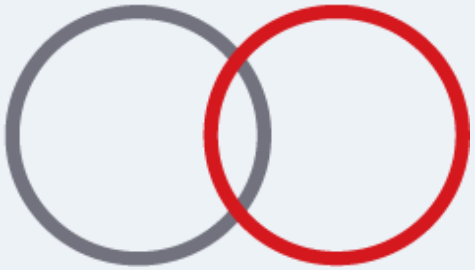
CER Data Capabilities & Insights

Cross-Sectional

examining relationships at a single point in time

Longitudinal

collecting prospective data



Dyadic

capturing data from patient and caregiver pairs

Subgroup Analyses

segmenting the data in different ways (e.g., by diagnosis, region, age)

Background

- **Adequate nutrition is critical** for prognosis, treatment tolerance, symptom management, and quality of life across the cancer continuum.
- **Malnutrition and nutrition-related symptoms remain common** and negatively affect outcomes.
- **Access to Registered Dietitian Nutritionists (RDNs) is inconsistent**, despite evidence linking nutrition services to improved outcomes.
- **Gaps in nutrition care may vary** by care setting, cancer type, and sociodemographic factors.
- **Patient-centered data are needed** to identify unmet needs, disparities, and barriers to nutrition services.

Research Question

What are cancer survivors' experiences with professional nutrition care since diagnosis, including sources of care, met and unmet needs, timing of need, and priority nutrition concerns, and how do these experiences vary by sociodemographic and clinical characteristics?

This study uses Cancer Experience Registry (CER) data to examine survivors':

- Access to and engagement with professional nutrition services
- Met and unmet nutrition care needs
- Variation by clinical, demographic, and care-setting factors

Sample and Analytic Approach

- **Sample:** **1,427 CER patients/survivors** in 12-month survey, collected between November 2022 - November 2024, which included the full set of nutrition service items.
- **Analytic approach:**
  - **Descriptive statistics** were used to summarize participant characteristics, with frequencies and percentages reported for all variables.
  - **Bivariate associations** for categorical variables were examined using chi-square tests.
  - **In multivariate analysis**, nutrition care need was modeled using multinomial logistic regression with met need as the reference category, and RDN engagement (yes/no) was modeled using binary logistic regression. Covariates that demonstrated significant associations ($p < .05$) with either primary outcome, nutrition care need or engagement with an RDN, were included in multivariable models.

Method and Key Measures

*Since being diagnosed with cancer, have you ever gotten **professional support** for eating and nutrition from any of the following care providers?*

Timing of Desired Nutrition Care

(Among those who wanted support; *select all that apply*)

- Before diagnosis
- At diagnosis
- During treatment
- After treatment
- At recurrence
- Cancer advanced

Provider Engagement

- Participants assessed receipt of nutrition services from 9 provider types (*select all that apply*).
- Primary provider-related outcome: **RDN engagement** (ever seen an RDN since diagnosis).

Areas of Desired Nutrition Services

(*select all that apply*)

- Symptom/side-effect management (e.g., nausea, taste changes)
- Weight support (maintain, gain, or lose)
- Healthy eating patterns
- Energy level
- Emotional/mental health support

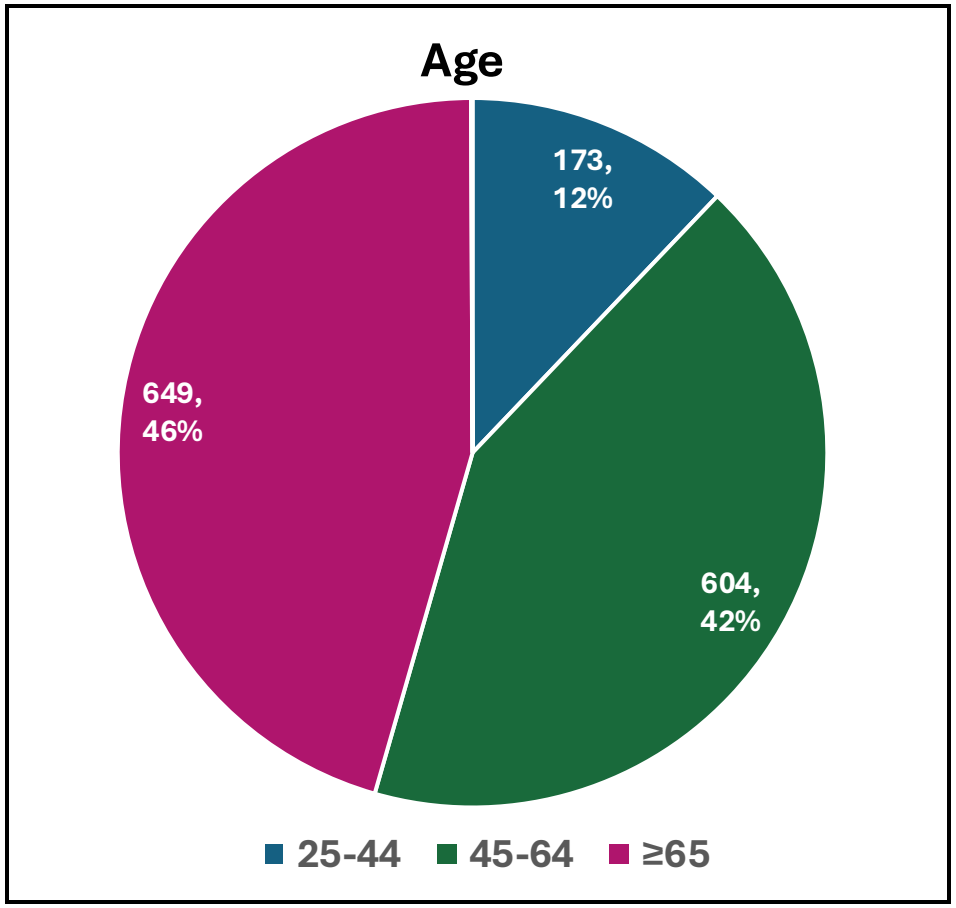
Method and Key Measures

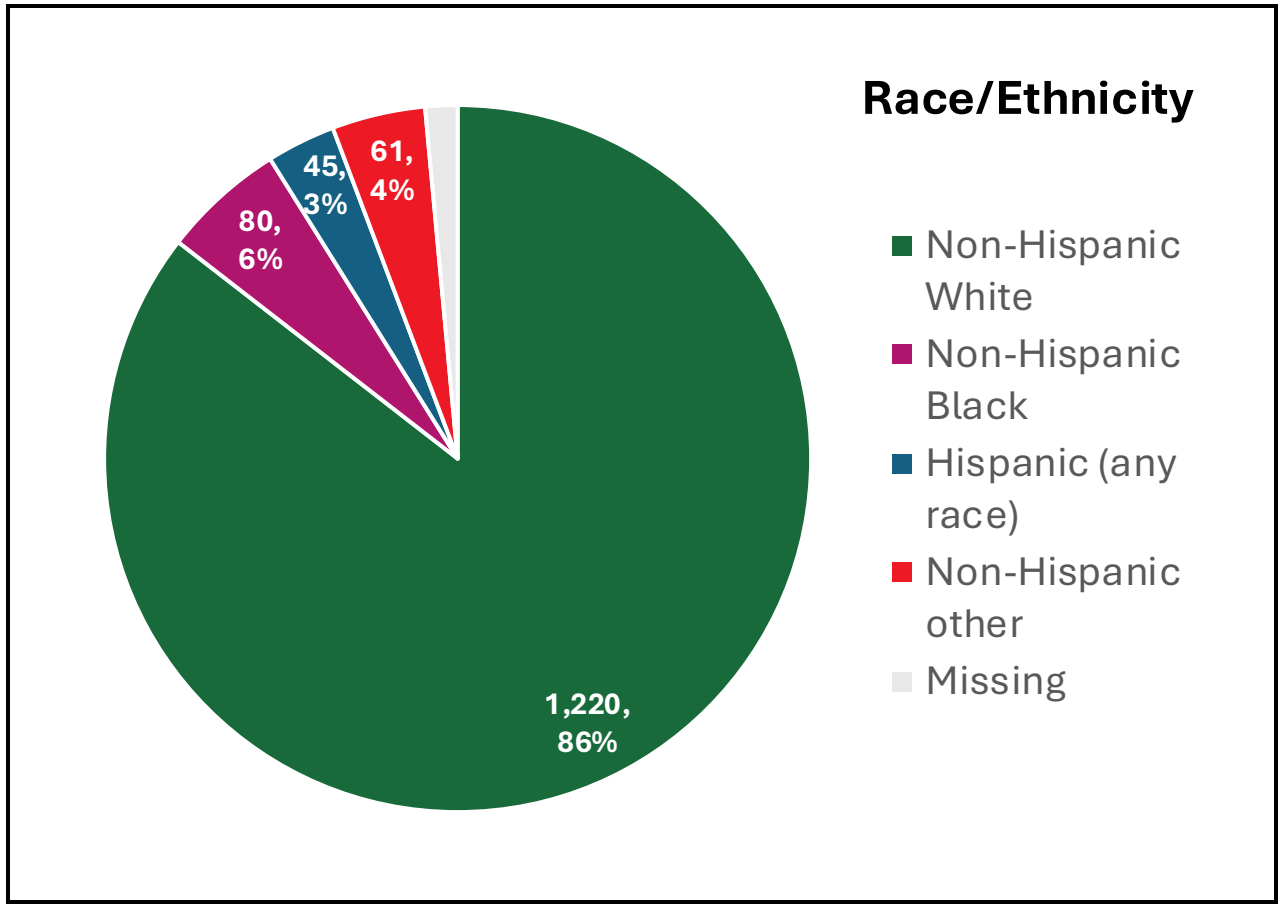
Nutrition Care Need

Assessed using a single item asking participants which statement best described their experience with eating and nutrition support since being diagnosed with cancer:

4 response options that reflect a combination of if they **wanted** care and if they **received** that care

Sample Characteristics (N=1,427)





Gender: 77% Women and **23% Men**

Geographic region: 89% Urban/Suburban and **10% Rural**

Sample Characteristics (N=1,427)

Sociodemographic characteristics	n (%)
Highest level of education	
College+	**1,065 (74.6)**
<College	356 (25.0)
Missing	6 (0.4)
Employment status	
Employed	533 (37.4)
Retired	**597 (41.8)**
Unemployed—disability	197 (13.8)
Unemployed—other	92 (6.5)
Missing	8 (0.6)
Insurance	
Private only	541 (37.9)
Government Only	**700 (49.1)**
Private + government	137 (9.6)
Uninsured	3 (0.2)
Other	26 (1.8)
Missing	20 (1.4)
Economic and social resources	
Food security	
High/marginal	1,202 (84.2)
Low	**119 (8.3)**
Very Low	**97 (6.8)**
Missing	9 (0.6)

Sociodemographic characteristics	n (%)
Caregiver status (family/friend)	
Did/does have a caregiver	**1,140 (79.9)**
Did not/does not have a caregiver	267 (18.7)
Missing	20 (1.4)
Time since diagnosis	
1 to <3 years	312 (21.9)
3 to <5 years	**354 (24.8)**
5 to <10 years	**399 (28.0)**
≥10 years	**360 (24.2)**
Missing	2 (0.1)
Primary cancer site	
Breast	**465 (32.6)**
Blood	422 (29.6)
Gastrointestinal	150 (10.5)
Genitourinary	104 (7.3)
Gynecologic	108 (7.6)
Lung	57 (4.0)
Head/neck	23 (1.6)
Other	98 (6.9)
Metastatic disease	
No	1,024 (71.8)
Yes	**403 (28.2)**
Recurrent disease	
No	1,017 (71.3)
Yes	**410 (28.7)**

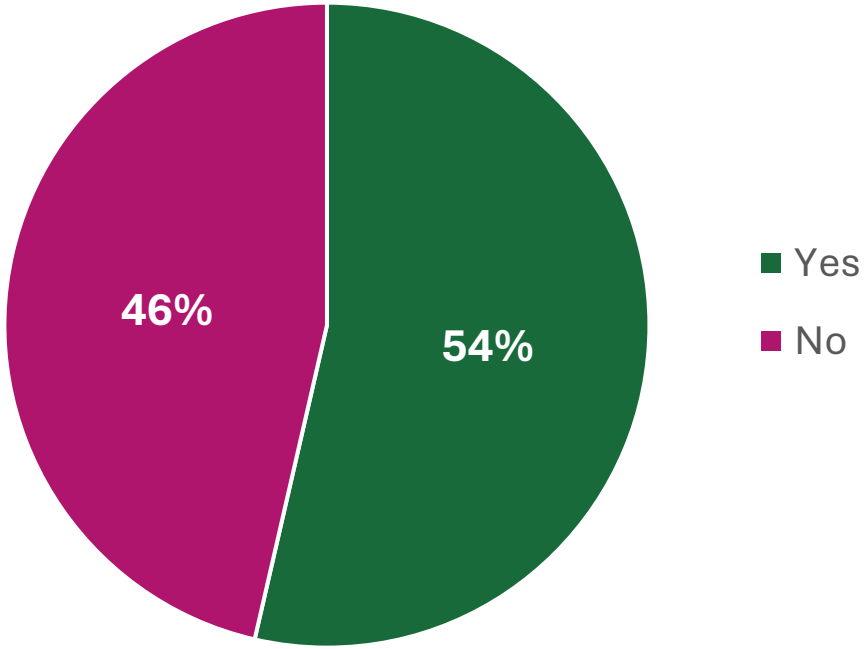
Sociodemographic characteristics	n (%)
Nutrition-impact symptoms	
None	538 (37.7)
1-2	382 (26.8)
≥3	**507 (35.5)**
Treatment history	
Chemotherapy	
No	446 (31.3)
Yes	981 (68.8)
Radiation therapy	
No	810 (56.8)
Yes	617 (43.2)
Immunotherapy	
No	1,126 (78.9)
Yes	301 (21.1)
Site of most cancer treatment	
Academic/Comprehensive	**655 (45.9)**
Community	417 (29.2)
Private oncology practice	230 (16.1)
VA/Military	12 (0.8)
Other	53 (3.7)
I'm not sure	18 (1.3)
Missing	42 (2.9)

Poll Question #1

*"What percentage of the total sample reported receiving **any nutrition services** since their cancer diagnosis, and what percentage reported receiving care from a **Registered Dietitian Nutritionist (RDN)**?"*

Results

More than half of respondents (53.6%) reported receiving some form of nutrition services since their cancer diagnosis.



Registered Dietitian Nutritionist (RDN)

- **39.3%** saw an RDN since diagnosis
  - 18.9% exclusively from an RDN
  - 20.4% RDN plus other providers
- **15.3%** RDN visit in the past 6 months

Other Provider Types

Participants received nutrition-related services from:

- Oncology doctor (18.0%)
- Primary care providers (15.4%)
- Oncology nurse (12.8%)

Types of Providers Seen for Nutrition Care Among Participants

Table 2. Types of Providers Seen for Nutrition Care Among Participants (N=1,427)				
	Since being diagnosed with cancer			
	This provider type seen	Only this provider type seen	This and other provider types seen	This provider type seen in past 6 months
	n (%)			
Registered dietitian nutritionist	**561 (39.3)**	**269 (18.9)**	**292 (20.4)**	**218 (15.3)**
Oncology doctor	257 (18.0)	38 (2.7)	219 (15.3)	96 (6.7)
Oncology nurse	182 (12.8)	19 (1.3)	163 (11.4)	73 (5.1)
Primary care doctor	219 (15.4)	39 (2.7)	180 (12.6)	118 (8.3)
Primary care nurse	52 (3.6)	7 (0.5)	45 (3.2)	19 (1.3)
Palliative care provider	42 (2.9)	7 (0.5)	35 (2.5)	22 (1.5)
Holistic provider	90 (6.3)	13 (0.9)	77 (5.4)	49 (3.4)
Pharmacist	41 (2.9)	3 (0.2)	37 (2.6)	19 (1.3)
Chiropractor	33 (2.3)	2 (0.1)	31 (2.2)	11 (0.8)

Nutrition Care Need by Cancer Diagnosis

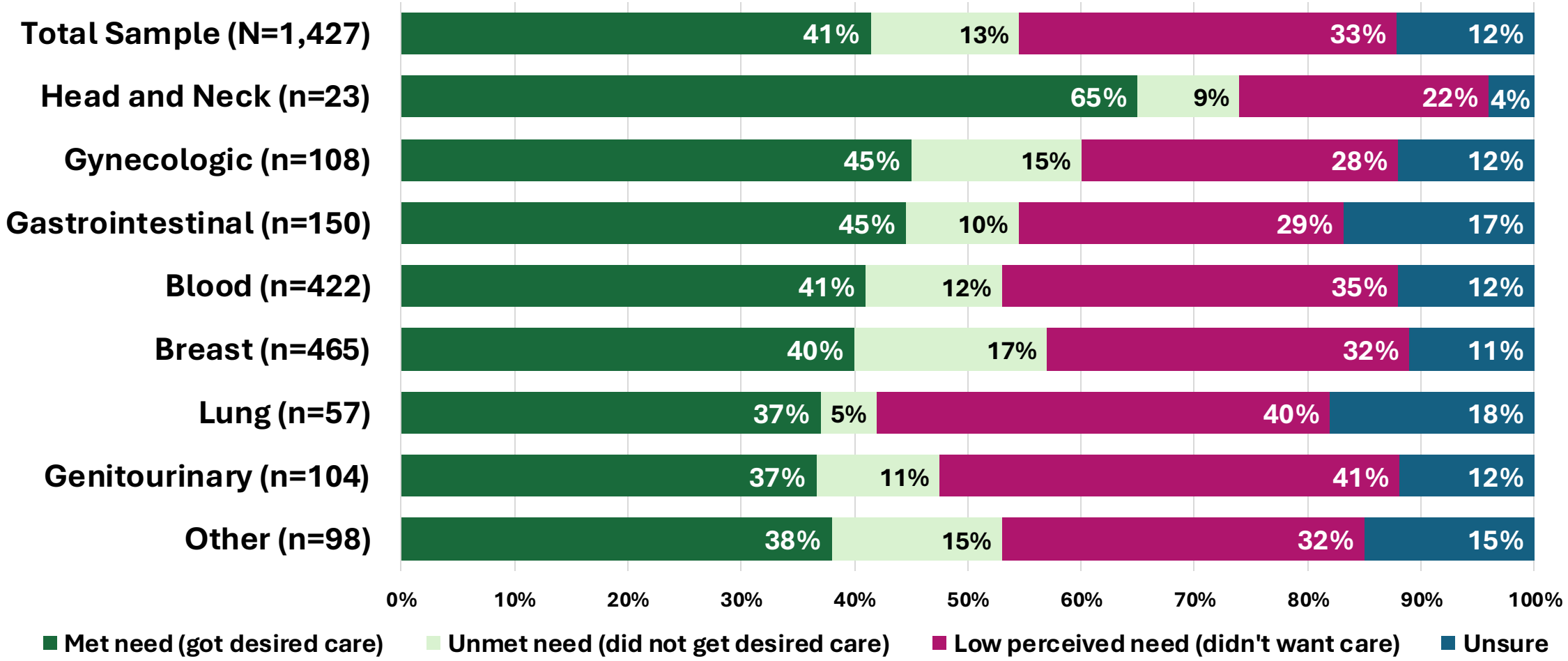
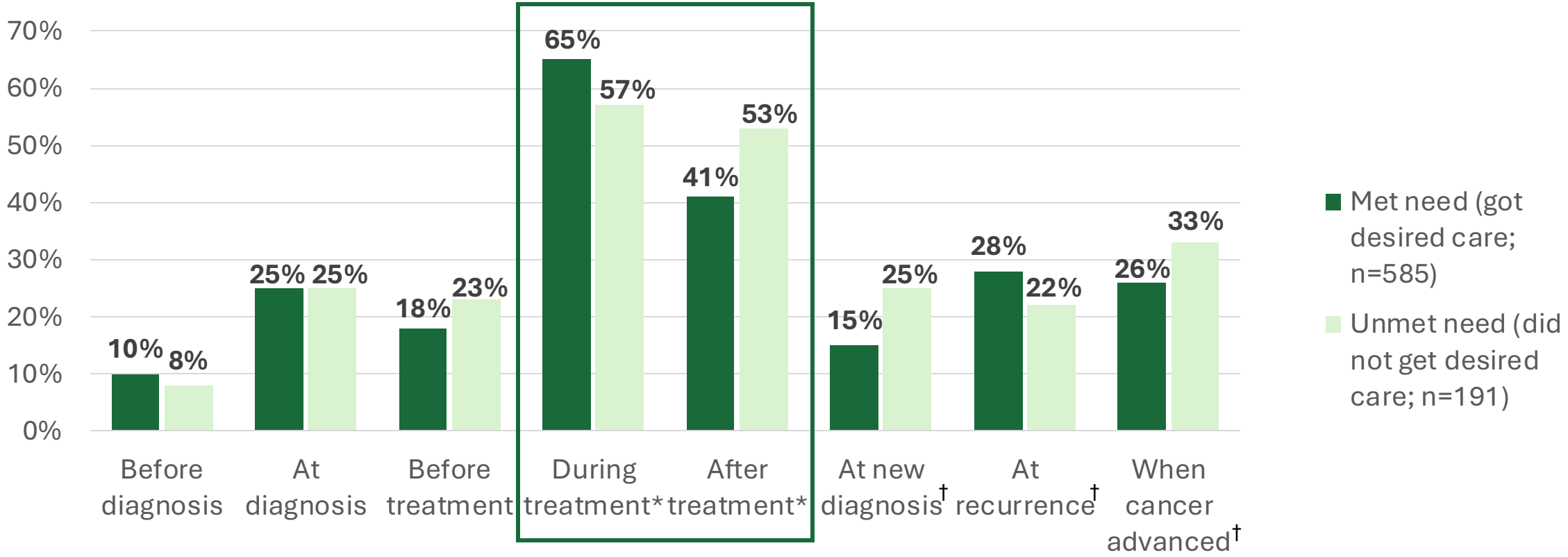


Figure adapted from manuscript currently under review: Nutrition Services in Oncology: A Survey of Patient Experiences, Needs, and Gaps in Care

Met vs. Unmet need: Timing of Desired Nutrition Care



*Timing of desired nutrition care, by whether they received professional care. Participants could select multiple time points; percentages do not sum to 100%. †Items applicable only to participants who experienced a new cancer within the past 12 months (n=45), a recurrence (n=225), or an advanced cancer diagnosis (excluding those metastatic at diagnosis; n=105). *Asterisks indicate significant group differences (χ^2, $p < .05$). Survey item: "When did you want professional support for eating and nutrition?" Participants could select all that applied.*

Figure adapted from manuscript currently under review: Nutrition Services in Oncology: A Survey of Patient Experiences, Needs, and Gaps in Care

Met vs. Unmet need: Areas of Desired Nutrition Services

Among participants who wanted nutrition care, healthy eating and symptom management were the most frequently endorsed areas overall.

Participants with Met Need

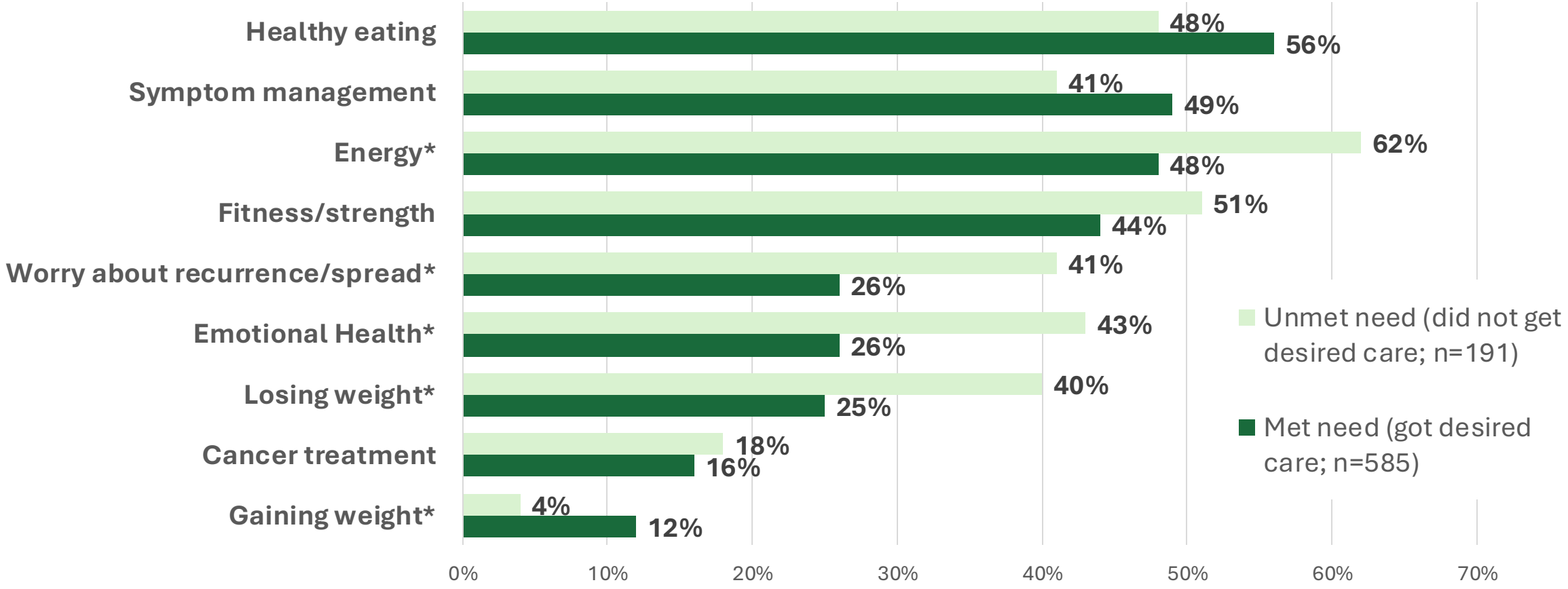
- Significantly more likely to endorse gaining weight (12.3% vs. 3.7%; $p < .05$)

Participants with Unmet Need significantly more likely to desire support for:

- Energy improvement (61.8% vs. 47.5%)
- Emotional health (42.9% vs. 25.8%)
- Worry about cancer recurrence or spread (41.4% vs. 26.2%)
- Losing weight (40.3% vs. 25.1%)

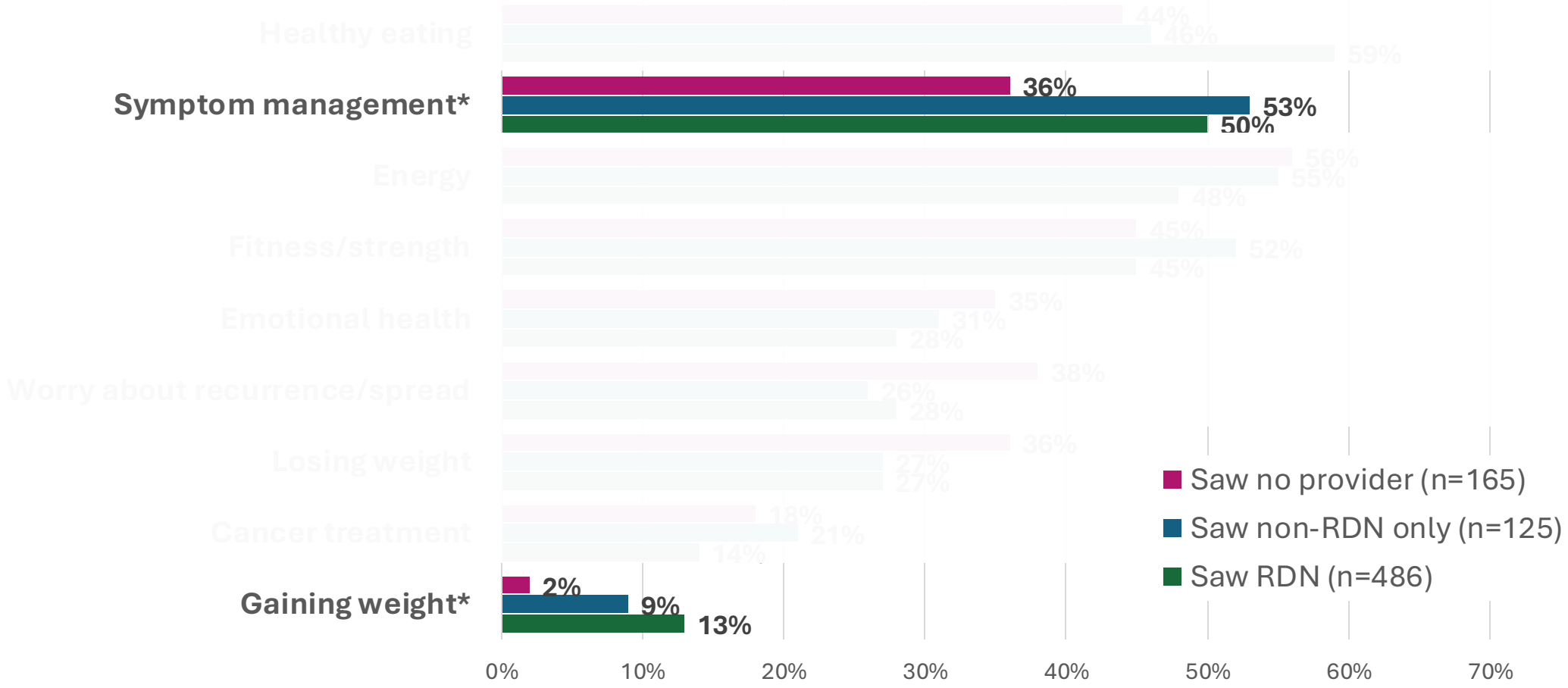
(all $p < .05$)

Met vs. Unmet need: Areas of Desired Nutrition Services



*Areas of desired nutrition services, by whether they received professional care. Participants could select multiple reasons; percentages do not sum to 100%. Categories are ordered by frequency of unmet need. *Asterisks indicate significant group differences (χ^2 test, $p < .05$). Survey item: "What eating and nutrition needs did you want or get professional support for?" Participants could select all that applied. Figure adapted from manuscript currently under review: Nutrition Services in Oncology: A Survey of Patient Experiences, Needs, and Gaps in Care*

Areas of Desired Nutrition Services by Care Type Received



*Areas of desired nutrition services, by whether they received professional care. Participants could select multiple reasons; percentages do not sum to 100%. Categories are ordered by frequency of unmet need. *Asterisks indicate significant group differences (χ^2 test, $p < .05$). Survey item: "What eating and nutrition needs did you want or get professional support for?" Participants could select all that applied. Figure adapted from manuscript currently under review: Nutrition Services in Oncology: A Survey of Patient Experiences, Needs, and Gaps in Care*

Multivariate Analysis: Three Models of Need and Engagement

Nutrition care need was modeled using multinomial logistic regression with **met need** as the reference category, and

RDN engagement (yes/no) was modeled using binary logistic regression.

Covariates that demonstrated significant associations ($p < .05$) with either primary outcome, nutrition care need or engagement with an RDN, were included in multivariable models.

Poll Question #2

*"Which group(s) had a **higher** likelihood of **unmet need** that others?"*

Factors Associated with Unmet Need (vs. Met Need)

In adjusted multinomial regression models:

Higher Likelihood of Unmet Need

- Age 25–44 years (RRR = 2.17 vs. ≥65)
- Women (RRR = 2.20)
- Very low food security (RRR = 2.16)
- No caregiver (RRR = 2.07)
- ≥3 nutrition-impact symptoms (RRR = 2.01)
- Private oncology practice (RRR = 2.08)

Lower Likelihood of Unmet Need

- Non-Hispanic Black participants (RRR = 0.46)
- Metastatic disease (RRR = 0.63)
- Receipt of chemotherapy (RRR = 0.66)
- Receipt of radiation therapy (RRR = 0.65)

Factors Associated with Unmet Need (vs. Met Need)

In sum:

Younger age, identifying as a woman, food insecurity, lack of caregiver support, and **high symptom burden** are strong correlates of unmet nutrition care need.

Factors Associated with Low Perceived Need (vs. Met Need)

In adjusted multinomial regression models:

Higher likelihood among:

- Rural residents (RRR = 1.55)
- < College education (RRR = 1.49)
- No caregiver (RRR = 2.54)
- Private oncology practice setting (RRR = 1.63)

Lower likelihood among:

- Non-Hispanic Black participants (RRR = 0.28)
- Symptoms (1–2 symptoms: RRR = 0.63; ≥3 symptoms: RRR = 0.47)
- Those receiving radiation therapy (RRR = 0.61)

Factors Associated with Low Perceived Need (vs. Met Need)

In sum:

Social determinants of health, particularly **rurality, education, caregiver support,** and **treatment setting**, influence whether individuals perceive, question, or deprioritize nutrition care.

Factors Associated with RDN Engagement

In adjusted binomial regression model:

More Likely to Have Seen an RDN

- Non-Hispanic Black (OR = 1.78)
- Non-Hispanic Other (OR = 1.85)
- Retired (OR = 1.50)
- 1–2 nutrition-impact symptoms (OR = 1.49)
- ≥3 symptoms (OR = 1.76)
- Head and neck cancer (OR = 3.32)
- Receipt of radiation therapy (OR = 1.56)

Less Likely to Have Seen an RDN

- No caregiver (OR = 0.43)
- Community cancer center (OR = 0.75)
- Private oncology practice (OR = 0.39)

→ **Factors Associated with RDN Engagement**

In sum:

RDN engagement is associated with **greater clinical complexity and symptom burden** but is reduced in **private practice settings** and among those **lacking caregiver** support.

Big Picture Takeaways

This study reveals a persistent and clinically meaningful gap between nutrition care needs and access to specialized dietetic services among cancer survivors.

1. Access Gap

- Nearly half of survivors reported no engagement with nutrition services.
- Only about one third saw an RDN despite high symptom burden and documented malnutrition risk.
- Engagement remains especially limited in private and community oncology settings.

2. Unmet Need Is Clinically and Socially Patterned

- Unmet need clusters among younger adults, women, individuals with very low food security, and those without caregiving support.
- Low perceived need and uncertainty are strongly linked to education, employment status, and structural barriers.
- Nutrition care inequities intersect with broader social determinants of health.

Big Picture Takeaways (continued)

3. Critical Timing Windows

- Demand for nutrition services peaks during active treatment and after treatment completion.
- Survivorship represents a key opportunity for structured nutrition integration.

4. Nutrition Care Extends Beyond Diet

- Unmet needs frequently include fatigue, emotional health, weight concerns, and fear of recurrence.
- RDN services support both physical recovery and psychosocial well-being.

5. System-Level Action Is Needed

- Standardized nutrition screening and automated referral pathways.
- Expanded RDN staffing and telehealth access.
- Equitable reimbursement and national standards for oncology nutrition care.

Final Insights & Opportunities for Action

Nutrition-related needs are well documented in oncology outpatients, particularly at diagnosis. Yet access to RDN services in outpatient oncology remains limited, with low staffing ratios nationally. Given:

- High prevalence of nutrition-impact symptoms
- Persistent unmet need
- Limited RDN staffing in many outpatient settings

There is a strong case for:

- Standardized nutrition screening integrated into routine oncology workflows
- Automated referral pathways to RDN services
- Improved RDN staffing ratios across oncology settings
- Early, systematic screening could better align clinical risk with timely referral and intervention, reducing the gap between patient needs and dietetic care

Thank you

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Oncology Nutrition

a dietetic practice group of the Academy of Nutrition and Dietetics

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APPENDIX (Extra slides)

Multivariable Multinomial and Logistic Regression Models of Nutrition Care Need and Engagement with a Registered Dietitian Nutritionist Since Cancer Diagnosis				
Independent Variable	Model 1: Nutrition Care Need (Multinomial) Ref category = Met Need			Model 2: Saw RDN (Logistic)
	Unmet Need vs Ref	Low Perceived Need vs Ref	Unsure vs Ref	Yes vs No
		RRR[a] (95% CI)		OR[b] (95% CI)
Sociodemographic characteristics				
Age				
≥65 (ref)				
45-64	1.44 (0.83, 2.48)	0.76 (0.52, 1.10)	0.90 (0.53, 1.54)	1.38 (0.98, 1.94)
25-44	2.17 (1.07, 4.41)	1.26 (0.74, 2.15)	1.19 (0.57, 2.50)	1.24 (0.77, 1.97)
Gender				
Man (ref)				
Woman	2.20 (1.21, 4.03)	0.71 (0.50, 1.01)	0.87 (0.53, 1.43)	1.06 (0.77, 1.47)
Race				
Non-Hispanic White (ref)				
Non-Hispanic Black	0.46 (0.22, 0.96)	0.28 (0.14, 0.56)	0.47 (0.22, 1.02)	1.78 (1.08, 2.94)
Hispanic (any race)	1.96 (0.90, 4.28)	0.65 (0.28, 1.52)	0.63 (0.20, 2.00)	0.91 (0.48, 1.74)
Non-Hispanic other	0.39 (0.15, 1.02)	0.92 (0.49, 1.74)	0.42 (0.16, 1.09)	1.85 (1.04, 3.29)
Geographic region (RUCA)				
Urban/suburban (ref)				
Rural	0.68 (0.36, 1.29)	1.55 (1.02, 2.35)	0.74 (0.39, 1.42)	0.87 (0.59, 1.28)
Highest level of education				
College+ (ref)				
<College	0.97 (0.63, 1.50)	1.49 (1.09, 2.03)	1.64 (1.09, 2.45)	0.78 (0.59, 1.03)
Employment status				
Employed (ref)				
Retired	0.91 (0.51, 1.62)	0.95 (0.64, 1.40)	0.97 (0.55, 1.73)	1.50 (1.05, 2.15)
Unemployed—disability	1.51 (0.89, 2.58)	0.88 (0.55, 1.43)	2.85 (1.64, 4.96)	1.32 (0.90, 1.93)
Unemployed—other	1.27 (0.64, 2.51)	1.14 (0.63, 2.07)	2.29 (1.14, 4.58)	1.11 (0.68, 1.81)

Multivariable Multinomial and Logistic Regression Models of Nutrition Care Need and Engagement with a Registered Dietitian Nutritionist Since Cancer Diagnosis				
Independent Variable	Model 1: Nutrition Care Need (Multinomial) Ref category = Met Need			Model 2: Saw RDN (Logistic)
	Unmet Need vs Ref	Low Perceived Need vs Ref	Unsure vs Ref	Yes vs No
		RRR[a] (95% CI)		OR[b] (95% CI)
Economic and social resources				
Food security (USDA)				
High/marginal (ref)				
Low	1.28 (0.70, 2.32)	0.79 (0.46, 1.37)	1.61 (0.87, 2.96)	1.13 (0.74, 1.73)
Very low	2.16 (1.17, 3.99)	0.77 (0.41, 1.45)	1.37 (0.68, 2.74)	1.04 (0.64, 1.67)
Caregiver status (family/friend)				
Did/does have a caregiver (ref)				
Did not/does not have a caregiver	2.07 (1.25, 3.42)	2.54 (1.73, 3.73)	2.70 (1.64, 4.45)	0.43 (0.30, 0.62)
Clinical characteristics				
Primary cancer site				
Breast (ref)				
Blood	0.66 (0.39, 1.11)	0.71 (0.47, 1.06)	0.82 (0.47, 1.44)	1.02 (0.71, 1.45)
Gastrointestinal	0.60 (0.31, 1.17)	0.70 (0.43, 1.13)	1.35 (0.73, 2.52)	1.29 (0.85, 1.95)
Genitourinary	1.26 (0.53, 2.98)	0.84 (0.46, 1.51)	1.04 (0.44, 2.44)	0.76 (0.44, 1.32)
Gynecologic	0.75 (0.38, 1.47)	0.72 (0.42, 1.24)	0.98 (0.47, 2.06)	1.27 (0.80, 2.01)
Lung	0.39 (0.11, 1.42)	1.29 (0.65, 2.56)	1.58 (0.65, 3.86)	0.55 (0.29, 1.05)
Head/neck	0.42 (0.08, 2.11)	0.36 (0.12, 1.12)	0.19 (0.02, 1.70)	3.32 (1.23, 8.98)
Other	0.96 (0.46, 1.99)	0.82 (0.45, 1.47)	1.05 (0.49, 2.25)	1.25 (0.76, 2.07)
Metastatic disease				
No (ref)				
Yes	0.63 (0.41, 0.96)	0.87 (0.64, 1.19)	0.66 (0.42, 1.02)	1.16 (0.88, 1.52)

Multivariable Multinomial and Logistic Regression Models of Nutrition Care Need and Engagement with a Registered Dietitian Nutritionist Since Cancer Diagnosis				
Independent Variable	Model 1: Nutrition Care Need (Multinomial) Ref category = Met Need			Model 2: Saw RDN (Logistic)
	Unmet Need vs Ref	Low Perceived Need vs Ref	Unsure vs Ref	Yes vs No
		RRR[a] (95% CI)		OR[b] (95% CI)
Treatment history				
Chemotherapy				
No (ref)				
Yes	0.66 (0.44, 0.98)	1.01 (0.74, 1.36)	0.81 (0.54, 1.22)	1.27 (0.97, 1.67)
Radiation therapy				
No (ref)				
Yes	0.65 (0.44, 0.97)	0.61 (0.46, 0.82)	0.66 (0.44, 0.98)	1.56 (1.21, 2.02)
Health care system characteristics				
Site of most cancer treatment				
Academic/Comprehensive (ref)				
Community	1.30 (0.86, 1.97)	1.09 (0.80, 1.48)	0.88 (0.56, 1.36)	0.75 (0.58, 0.99)
Private oncology practice	2.08 (1.26, 3.43)	1.63 (1.11, 2.40)	1.84 (1.11, 3.06)	0.39 (0.27, 0.55)
VA/Military	0.57 (0.05, 6.56)	1.09 (0.30, 3.95)	Too small	1.28 (0.36, 4.56)
Other	2.25 (0.89, 5.71)	1.17 (0.56, 2.44)	2.77 (1.20, 6.40)	0.50 (0.26, 0.95)
I'm not sure	0.65 (0.07, 6.02)	1.80 (0.53, 6.11)	3.09 (0.81, 11.8)	0.35 (0.11, 1.12)

Findings: Persistent Gaps in Specialized Nutrition Care

This study highlights a substantial gap between nutrition care need and access to specialized services among cancer survivors.

- **Although more than half of respondents reported receiving some form of nutrition care, only about one third had seen a Registered Dietitian Nutritionist (RDN).**
- Fewer than 20% relied exclusively on RDNs, with many receiving nutrition guidance from non-specialist clinicians.
- More than half of those who desired nutrition care reported unmet need during treatment and after treatment completion.
- **These findings emerged in a cohort with:**
  - High symptom burden (35.5% reporting ≥3 nutrition-impact symptoms)
  - Socioeconomic vulnerability, including low or very low food security
  - Variation in care delivery settings

Findings: Unmet Need Extends Beyond Diet

Unmet nutrition care needs were not limited to dietary concerns. Participants with unmet need were more likely to report:

- Desire for support with energy and fatigue
- Emotional health concerns
- Worry about cancer recurrence or spread
- Weight loss management

This suggests nutrition services intersect with both physical and psychosocial survivorship

<u>Timing patterns reinforce this:</u>

- Demand peaks during active treatment
- Unmet need is especially pronounced after treatment completion
- This contrasts with some head and neck cancer populations, where pre-treatment nutrition counseling is often prioritized.

Findings: Structural & Social Determinants of Nutrition Care Access

- **Multivariable analyses highlight structural drivers of unmet, low perceived, and uncertain need. Unmet need was more common among:** Younger adults, women, individuals with very low food security, those without caregiving support, and patients treated in private oncology practices
- **Low perceived need and uncertainty were strongly associated with:** Lower educational attainment, Unemployment (including disability-related), Absence of caregiver support
- Education and economic stability likely influence awareness of RDN benefits, perceived affordability, and prioritization of supportive services.
- The independent association between very low food security and unmet need raises important equity concerns, underscoring the need to link oncology patients to both clinical nutrition care and community food resources.

Findings: System-Level Implications & Policy Considerations

RDN engagement was more likely among patients with clear clinical risk (e.g., high symptom burden, head and neck cancer, radiation therapy), suggesting referral is often reactive rather than systematic. However, engagement was lower in:

- Community cancer centers
- Private oncology practices
- Patients without caregiving support

<u>These findings support several system-level actions:</u>

- Embed RDNs within multidisciplinary oncology teams across all settings
- Expand telehealth models to reach rural and community-based populations
- Implement national standards for nutrition screening and referral
- Establish equitable reimbursement mechanisms for oncology nutrition care
- Evidence suggests appropriate nutritional support can improve outcomes and reduce costs associated with malnutrition-related complications.