

Improving Patient & Caregiver Knowledge and Communication about Cancer Cachexia

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BACKGROUND

- Cancer cachexia is a complex, systemic metabolic condition that impacts up to 80% of cancer patients and is characterized by significant unintended weight loss, reduction in muscle function, fatigue, and poor healthrelated quality of life.
- There is significant lack of understanding and communication around cancer cachexia among patients, caregivers, and healthcare providers.
- To increase knowledge and communication about cachexia, we co-created a cancer cachexia lexicon, establishing a shared set of plain language terminology for patients, caregivers, providers, and advocates.
- We evaluated the efficacy of the lexicon in increasing knowledge and communication about cancer cachexia among patients and caregivers.

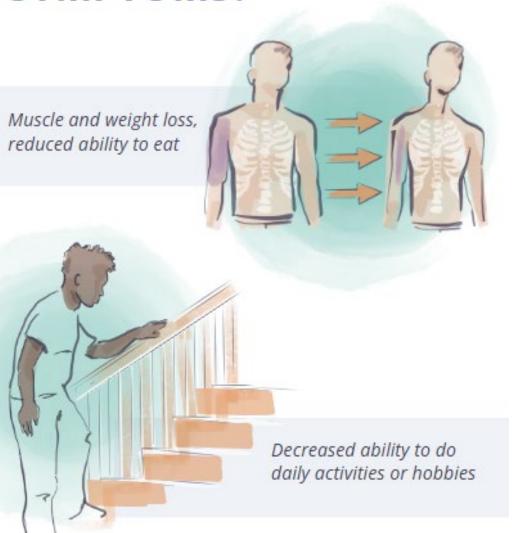
HAVE YOU HEARD ABOUT CACHEXIA?

[kuh-kek-see-uh] Cachexia is a complex condition that can include significant weight loss, loss of muscle mass, physical inactivity, and metabolic disruptions including fatigue, nausea, and loss of concentration. Weight loss can happen during cancer treatment. Cachexia is not a side effect of treatment; it is a different condition. Significant, lifestyle altering, and unmanageable weight loss should be taken seriously.

Eating became a chore...lt

FRANKLY SPEAKING ABOUT CANCER

WHAT ARE THE SYMPTOMS?



IF YOU ARE EXPERIENCING SYMPTOMS OF

CACHEXIA...

Ask your oncology clinician to check for a cachexia diagnosis. Current research suggests a team approach is best to address the symptoms of cachexia. This may include physical therapy, nutritional support, and palliative care.

Ask your care team to speak to specialists like:

Dietitians who provide nutritional counseling

 Physical therapists who help improve movement and manage pain

 Occupational therapists who help adapt how you do daily activities

 Social workers who help you find resources and support

 Mental health professionals who provide support for your mental and emotional wellbeing

 Palliative care specialists who can help improve quality of life by addressing symptoms of cachexia

• Endocrinologists who specialize in



WHO IS AT RISK?

- Cachexia can affect anyone with a chronic illness regardless of their weight
- Cachexia is a distinct diagnosis separate from the side effects of treatment
- People with a diagnosis of pancreatic, lung, head and neck, colorectal, ovarian, and liver cancers are at higher risk of developing cachexia

QUESTIONS?

Please visit our website: www.CancerSupportCommunity.org/Cancer-Cachexia or contact our toll-free Cancer Support Helpline®

Pfizer

METHODS

- 191 participants (156 patients; 35 caregivers) representing diverse cancer types and stages completed the survey.
- 36% had been diagnosed with cachexia, and over 90% had experienced at least three symptoms associated with cachexia.
- The survey used a pre- and post- design in which participants: 1) reported baseline knowledge and communication around cachexia; 2) reviewed the tool; 3) rated the tool for clarity, acceptability, and resonance; and 4) re-assessed cachexia knowledge and intended communication.
- Data were analyzed using descriptive statistics, t-tests, and McNemar's tests.

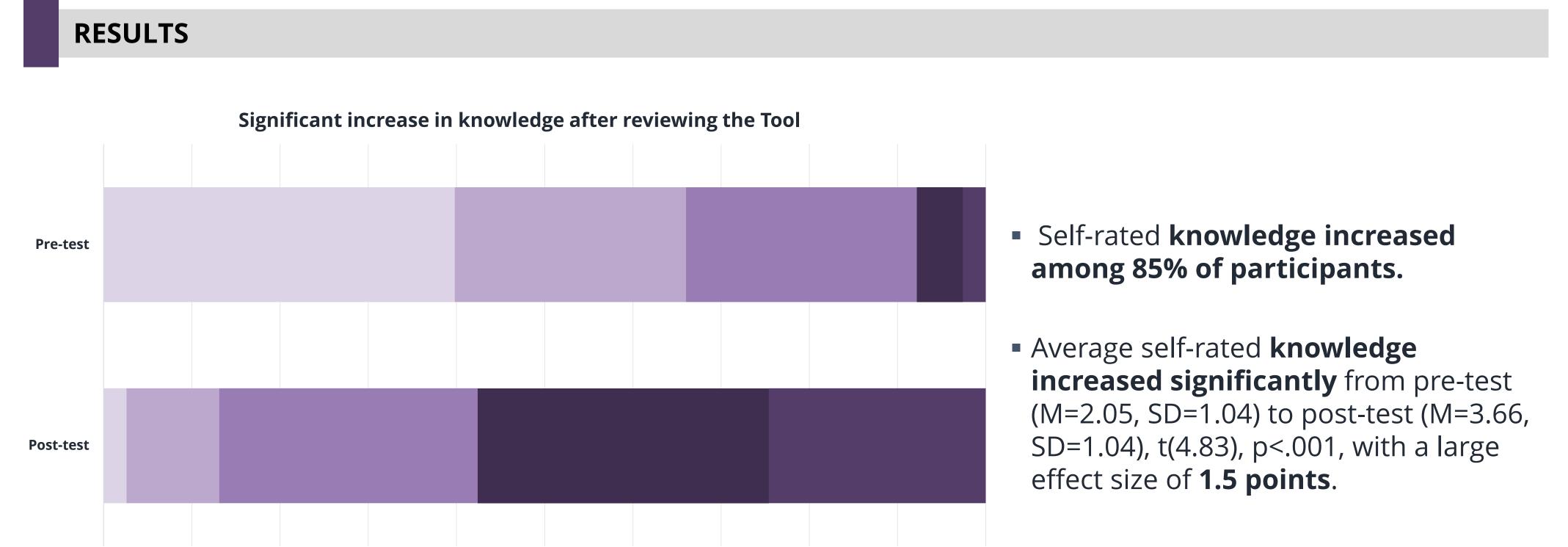
PARTICIPANTS

Participant Characteristics	n/mean	%/SD
Cancer Experience		
Patient	156	82%
Caregiver	35	18%
Cachexia diagnosis		



Figure 1: Cancer Cachexia Lexicon Engagement Tool for Patients & Caregivers

Reduced appetite and



Percent of participants

Diagnosed with cachexia	65	34%
Not diagnosed	90	47%
Unsure	36	19%
Tumor type		
Breast	66	34%
Colorectal	30	16%
Lung	25	13%
Pancreatic	15	8%
Other	55	29%
Stage		
0-I	46	24%
H	48	25%
	42	22%
IV	47	25%
Unsure / Unstaged	8	4%
Age, years (Range: 33-91)	49	13
Gender		
Woman	152	80%
Man	36	19%
Prefer not to share	3	1.0%
Race & Ethnicity		
Non-Hispanic White	119	62%



- Before reviewing the Engagement Tool, only 16% of participants accurately identified the symptoms associated with cachexia, compared to **69% of** participants at post-test.
- A significant proportion of participants increased the accuracy of their **knowledge** around cachexia symptoms between pre and post-test based on McNemar's test (p<.001).
- After reviewing the Engagement Tool, **77% of participants** were willing to talk to their provider about cachexia, compared to only **38% at pre-test**.
- Most participants were willing to share the Tool with their **providers**, as well as

Hispanic / Latino

Multiple races

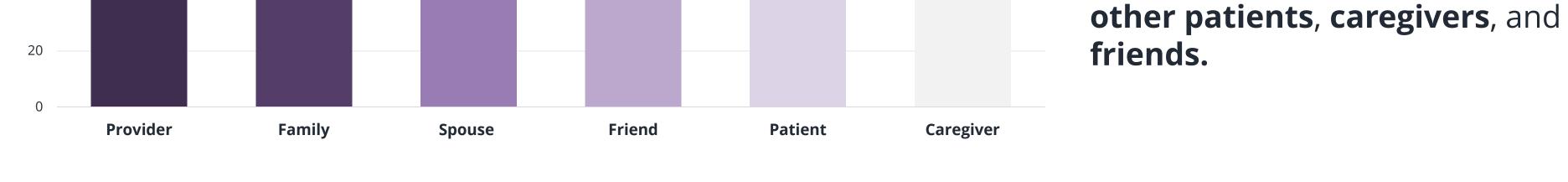
Native Hawaiian

Prefer not to share

Level of education

N=200

High school degree	16	9%
Some college	33	17%
Associate's degree	35	18%
Bachelor's degree	69	36%
Graduate degree	38	20%



CONCLUSIONS AND IMPLICATIONS

Reviewing the Engagement Tool was associated with **increased self-rated knowledge**, **increased accuracy of knowledge**, and **increased willingness to communicate** about cancer cachexia.

• Coordinated dissemination of the tool in diverse venues and formats may encourage communication around the condition, increase diagnosis, and connect patients and caregivers with supportive care.

Educational interventions around cancer cachexia are essential in raising awareness around the condition, increasing patient-provider communication, and increase the rate of diagnosis and support.

CANCER SUPPORT

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International Conference of the Society on Sarcopenia, Cachexia and Wasting Disorders, December 2024

36

14

9

19%

7%

6%

1%

5%

Please contact anewell@cancersupportcommunity.org for additional information

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