

# Stomach Cancer Specialty Registry Report 2017

## What is the Stomach Cancer Specialty Registry?

Both stomach cancer and cancer of the esophagus are relatively rare cancers. For stomach cancer, there are expected to be approximately 28,000 new diagnoses in 2017, mostly in men. Approximately 13,300 men and 3,500 women are expected to be diagnosed with cancer of the esophagus in 2017 (ACS, 2016). Stomach and esophageal cancer produce few signs and symptoms in the early stages, which results in patients frequently being diagnosed in later stages, resulting in a need to even better understand the unique needs of this patient population.

The Stomach Cancer Specialty Registry, which began accepting participants in February 2016, documents the experiences of a cross-section of people living with gastric cancer. The Stomach Cancer Advisory Council—made up of gastric cancer specialists and other oncologists, behavioral scientists, patient advocates, and industry representatives—supports the efforts of the Registry by providing continued support and guidance on outreach, research, and the dissemination of findings (see a list of Advisory Council members at [www.cancersupportcommunity.org/RegistryIndexReport2017](http://www.cancersupportcommunity.org/RegistryIndexReport2017)).



# KEY FINDINGS

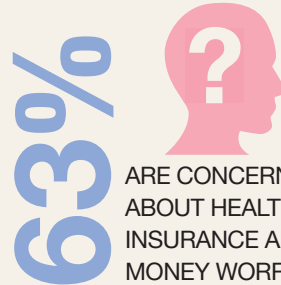
THIS REPORT CONTAINS NUMEROUS INSIGHTS INTO THE STOMACH AND ESOPHAGEAL CANCER EXPERIENCE. KEY FINDINGS INCLUDE:



QUALITY OF LIFE

63%

ARE TOO TIRED TO DO THE THINGS THEY NEED OR WANT TO DO



ARE CONCERNED ABOUT HEALTH INSURANCE AND MONEY WORRIES

44%

ARE AT RISK FOR CLINICAL DEPRESSION

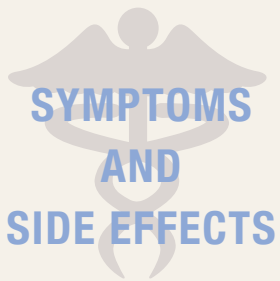


DOCTOR-PATIENT COMMUNICATION

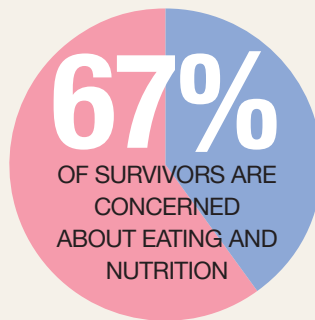
LESS THAN 30% OF PARTICIPANTS HAD DISCUSSIONS WITH THEIR DOCTOR ABOUT THE PSYCHOLOGICAL AND EMOTIONAL IMPACT OF THEIR DISEASE

WHILE 78% WERE INVOLVED IN TREATMENT DECISION-MAKING, ONLY 35% FELT PREPARED TO MAKE A DECISION

71% OF STOMACH CANCER PATIENTS SAID THAT SPIRITUAL CARE HAS BEEN AN INTEGRAL PART OF THEIR CANCER CARE PLAN



SYMPTOMS AND SIDE EFFECTS



OVER A QUARTER OF PARTICIPANTS (28%) INDICATED THEY HAD SOME PROBLEMS EATING SOLID FOOD

OVER 40% HAD PAINFUL STOMACH DISCOMFORT



COST OF CARE

36% OF STOMACH AND ESOPHAGEAL CANCER PARTICIPANTS EXPERIENCED SIGNIFICANT LEVELS OF INTRUSIVE THOUGHTS ABOUT MANAGING CARE COSTS

60% REPORTED PAYING AT LEAST \$250 IN OUT-OF-POCKET COSTS ON A MONTHLY BASIS

ONLY 20% OF PARTICIPANTS REPORTED THAT A MEMBER OF THEIR CARE TEAM SPOKE TO THEM ABOUT COST OF CARE

# Who is in the Registry?

This 2017 report analyzes survey responses from 53 stomach and esophageal cancer patients who reside in the United States and completed survey questions from the opening of the Registry in February 2016 to December 31, 2016 (in the tables below, the number of responses is 53 unless otherwise noted).

<i>FIGURE 1</i> <b>STOMACH CANCER SPECIALTY REGISTRY SURVEY DEMOGRAPHICS</b>		
	<i>NUMBER OF PARTICIPANTS (n)</i>	<i>PERCENT</i>
<b>AGE</b> (n = 53)		
Mean age	57.1 years, SD = 13.9	Range: 26 to 83
18-44	12	23%
45-64	26	49%
>=65	15	28%
<b>GENDER</b> (n = 39)		
Male	20	51%
Female	19	49%
<b>RACE</b> (n = 39)		
White	32	82%
Black or African American	3	8%
<b>NON-HISPANIC ETHNICITY</b> (n = 39)		
	32	82%
<b>EDUCATION</b> (n = 39)		
High school or less	7	18%
Associate degree or some college	9	23%
Bachelor degree	7	18%
Graduate degree or higher	15	39%
<b>REGION</b> (n = 49)		
Urban	11	22%
Suburban	26	53%
Rural	11	22%
<b>EMPLOYMENT STATUS</b> (n = 36)		
Full-time	5	14%
Part-time	1	3%
Retired	11	31%
Not employed due to disability	16	44%
Not employed (reason not specified)	3	8%
<b>ANNUAL INCOME</b> (n = 33)		
<\$40K	12	37%
\$40-59.9K	5	15%
\$60-79.9K	1	3%
\$80-99.9K	2	6%
\$100K+	4	12%
Prefer not to share	9	27%

*Note: Table data are for stomach cancer and esophageal cancer respondents combined.*

**FIGURE 2 CANCER STAGE, TIME SINCE DIAGNOSIS AND CANCER STATUS OF SURVEY PARTICIPANTS**

	NUMBER OF PARTICIPANTS (n)	PERCENT
<b>STAGE AT DIAGNOSIS</b>	(n = 29)	
Stage I	4	14%
Stage II	6	21%
Stage III	5	17%
Stage IV	12	41%
I don't know	2	7%
<b>TIME SINCE DIAGNOSIS</b>	(n = 30)	
<1 year	5	17%
1–1.9 years	4	13%
2–4.9 years	11	37%
>=5 years	10	33%
<b>METASTATIC</b>	(n = 30)	
	9	30%
<b>RECURRENCE</b>	(n = 30)	
	5	17%

Note: Table data is for stomach cancer and esophageal cancer respondents combined.

A majority of respondents (63%) were currently or most recently receiving first-line therapy—first-time drug treatment. One-quarter (25%) identified as second-, third-, or later line therapies, treatments for when previous drugs have stopped working.

## What are we learning?

### CANCER-RELATED DISTRESS

A cancer diagnosis is associated with significant distress. The current understanding of the emotional and psychological needs of patients with stomach cancer is still inadequate. Figure 3 presents the 10 items that most respondents were moderately, seriously, or very seriously concerned about according to CancerSupportSource®, a validated distress screening instrument.<sup>1</sup>

CancerSupportSource features a depression subscale which demonstrated that 44% of gastric and esophageal cancer respondents were at risk for clinical depression.

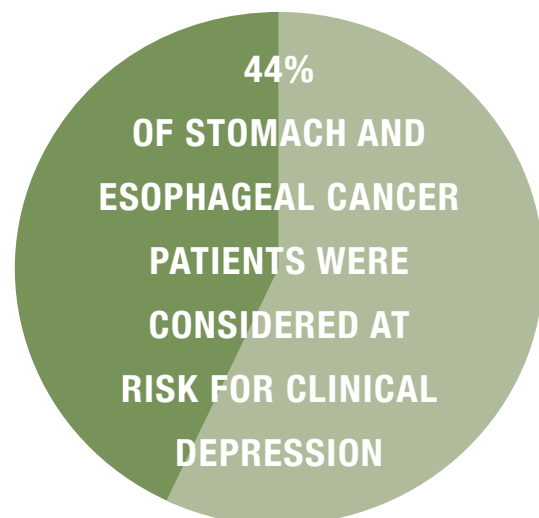
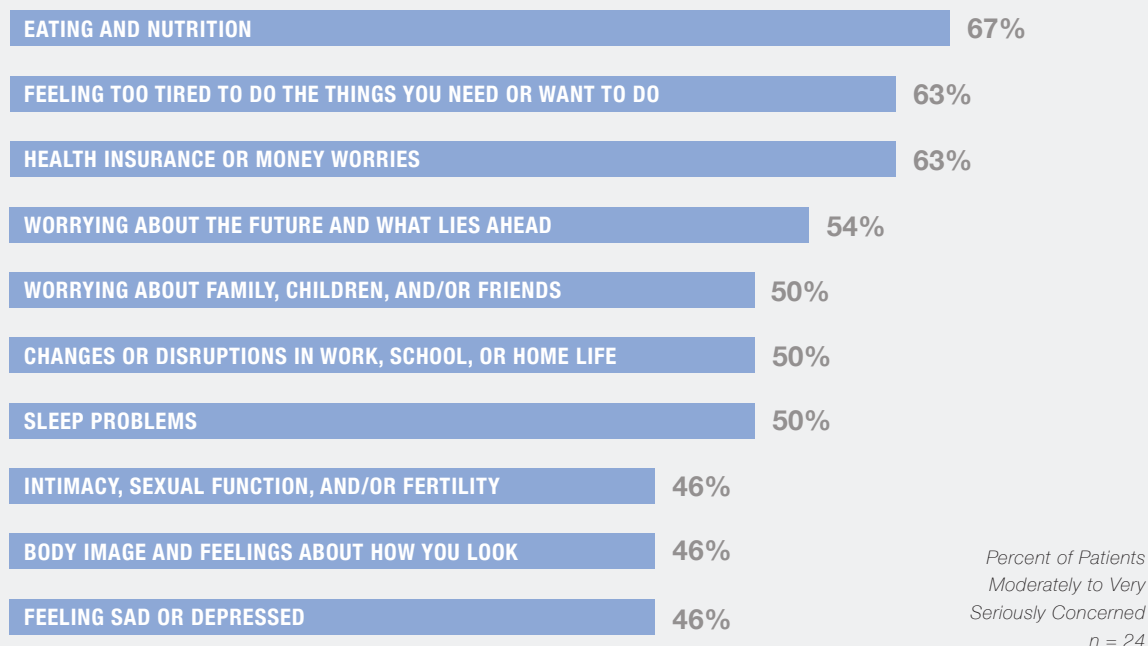


FIGURE 3 **TOP 10 CONCERNS ACROSS STOMACH AND ESOPHAGEAL PARTICIPANTS**



### PATIENTS VALUE

- Independence
- Support of family and friends
- Freedom from pain
- Easy, day-to-day living

### QUALITY OF LIFE IN STOMACH CANCER

Patients describe cancer’s impact on their quality of life in different ways, and delineating how people talk about what quality of life means to them can go a long way toward understanding what patients value in their cancer experience. Figure 4 presents a cross-section of patient responses to two questions about what quality of life means to them. Common themes emerge: the desire to maintain independence, the support of family and friends, living without pain or discomfort, and the ability—however infrequent—to go about their daily life unimpeded by signs of their disease.

Eating is an important aspect of daily living and can significantly influence quality of life and social well-being. For people living with stomach cancer, eating,

in particular, is a significant challenge, which can negatively affect a person’s intake of food and, therefore, overall health and the body’s ability to fight the disease. Respondents were asked to rate their experience—on a scale from “not at all” to “very much”—with specific issues related to eating and drinking during the week prior to completing the survey. Among seven stomach cancer respondents, 28% reported having at least quite a bit of problems eating solid foods. Pureed/soft foods and liquids were more palatable: 14% reported experiencing just a little bit of problem eating pureed/soft foods and 29% had a little bit of problem drinking liquids. Acid reflux is a common symptom of stomach cancer and 43% reported experiencing quite a bit to very much a problem with bile or stomach acid entering their mouth. An equal portion reported similar degrees of problems with heartburn and acid indigestion. General discomfort and pain in the stomach area were cited as quite a bit of a problem by 43% and 14% of respondents, respectively, and 14% experienced more than quite a bit of dry mouth.

FIGURE 4

## RESPONDENTS' VIEWS ON QUALITY OF LIFE

### HOW DO YOU DEFINE QUALITY OF LIFE?

- *Plenty of love and people interaction;  
good health and good food.*
- *Being able to enjoy family and friends,  
being able to function physically  
in a modest fashion.*
- *Managing day-to-day activities on  
your own, and doing the things that make  
you happy and feel alive.*
- *Being in physical comfort and  
enjoying activities.*
- *Able to eat and drink without major  
difficulty, able to see my family and friends,  
and able to do things on my own  
free of major discomfort.*

### WHAT IS MOST IMPORTANT TO YOU NOW?

- *Giving back to others and returning  
my life to full activity, especially with family.*
- *Making sure my family is provided for after  
my death; giving back as much as I am able.*
- *Being happy and living my life fully.*
- *Feeling the best I can despite my disease,  
feeling positive and thankful for myself  
and the people I come into contact with.*
- *Seeing and talking to my family  
and friends.*

## TREATMENT DECISION-MAKING AND PLANNING

Treatment options for stomach and esophageal cancer patients vary based on a number of factors: disease stage, medical history, and patient preference. Treatments generally include chemotherapy, radiation, targeted therapies (drugs that target specific proteins or elements of cancerous cells), surgery, and, in the case of esophageal cancer, endoscopic procedures. For many late-stage patients, these treatments are used in a palliative context to alleviate pain and discomfort brought on by symptoms and side effects.

Shared decision-making is a critical element of treatment. Although patients report being very involved in treatment decision-making (78% quite a bit to very much), they are far less likely to report feeling prepared to discuss treatment options with their doctor (Figure 5). Sixty-five percent felt they were not fully prepared for treatment, and 22% indicated they were not prepared at all.

## PALLIATIVE AND SPIRITUAL CARE FOR STOMACH CANCER PATIENTS

For stomach cancer patients, doctor-patient communication around palliative care can be especially important, and at times, difficult. Health care providers must manage expectations about the goals of the treatment plan, and accurately convey the scope of the disease. Among seven stomach cancer patients that responded, 29% reported that their doctor discussed psychological aspects of palliative care, 43% indicated social aspects were discussed, and 57% said their doctor talked about physical care—managing pain and symptoms. In addition, 29% had discussions about the spiritual aspects of palliative care.

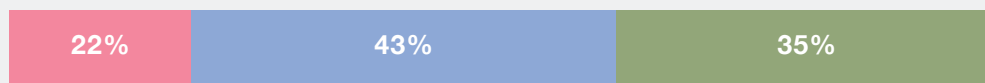
For some stomach cancer patients, spirituality and religion can be an important way to cope with cancer-related distress and to find meaning out of the cancer experience. Among seven stomach cancer respondents, 71% reported that spirituality is quite a bit or very important to them; 43% reported that religion was quite a bit or very important to them, and 71% of respondents said that spiritual care has been an integral part of their cancer care plan.

**FIGURE 5 TREATMENT DECISION-MAKING PROCESS:  
STOMACH AND ESOPHAGEAL CANCER**

**KNOWLEDGEABLE**



**PREPARED**



**INVOLVED**



- Not at all
- A little bit or Somewhat
- Quite a bit or Very much

n = 24

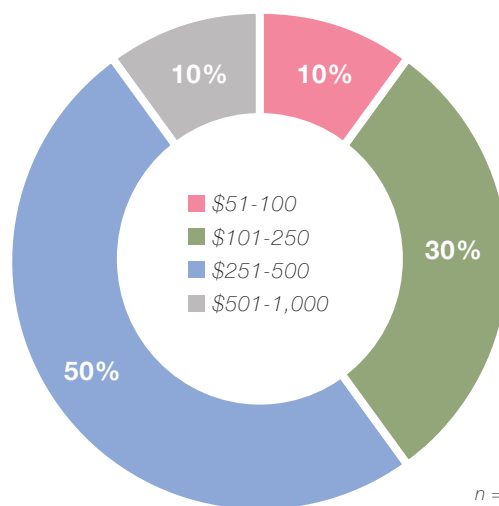
**COST OF CARE**

Thirty-six percent of stomach and esophageal cancer respondents reported significant levels of intrusive thoughts about their ability to manage costs of their cancer care, according to the Impact of Events Scale<sup>3</sup>.

Yet despite the evident anxieties associated with paying for their care, only 20% of stomach and esophageal cancer respondents reported that a member of their care team spoke to them about cost. Insurance coverage can mask the financial impact of medical care on the patient experience. Respondents were asked to quantify monthly out-of-pocket costs related to their cancer care and after care, 60% reported paying at least \$250 month in out-of-pocket costs (Figure 6).

Over one-third (36%) of stomach and esophageal cancer participants experienced significant levels of intrusive thoughts about managing care costs.

**FIGURE 6 MONTHLY  
OUT-OF-POCKET COSTS**



n = 10



# Learn More

For more information and to see our other specialty reports please visit:  
[www.cancersupportcommunity.org/RegistryIndexReport2017](http://www.cancersupportcommunity.org/RegistryIndexReport2017)

- Breast Cancer Specialty Registry Report
- Caregiver Specialty Registry Report
- Chronic Lymphocytic Leukemia (CLL) Specialty Registry Report
- Chronic Myeloid Leukemia (CML) Specialty Registry Report
- General Registry Report
- Lung Cancer Specialty Registry Report
- Melanoma Specialty Registry Report
- Metastatic Breast Cancer Specialty Registry Report
- Multiple Myeloma Specialty Registry Report
- Prostate Cancer Specialty Registry Report



1. Miller M. F., Mullins, C.D., Onukwugha, E., Golant, M., & Buzaglo, J.S. Discriminatory power of a 25-item distress screening tool: a cross-sectional survey of 251 cancer survivors. *Quality of Life Research*, 23, 2855-2863.
2. Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S.,...Hays, R. D. on behalf of the PROMIS Cooperative Group. (2010). Initial item banks and first wave testing of the Patient-Reported Outcomes Measurement Information System (PROMIS) network: 2005-2008. *Journal of Clinical Epidemiology*, 63(11), 1179-94.
3. Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine*, 41(3), 209-218.

#### ACKNOWLEDGMENTS

The Cancer Experience Registry: Gastric Cancer is made possible thanks to the support of Lilly Oncology as the Inaugural Sponsor.

Designed by Yolanda Cuomo Design, NYC; Photographs © Ed Cunicelli