Chronic Myeloid Leukemia (CML) Specialty Registry Report 2017

What is the CML Specialty Registry?

Chronic myeloid leukemia (CML) is a slow-growing blood cancer that begins in the bone marrow and, as it grows, can enter the blood stream and spread to other parts of the body. An estimated 8,950 new cases in the United States are expected in 2017, more than ten percent of all expected new leukemia cases (American Cancer Society, 2017), and prevalence is projected to be approximately 180,000 by 2050 (Howlader et al, SEER, 2015; Siegel et al, *CA: A Cancer Journal for Clinicians*, 2017; Huang, *Cancer*, 2012).

New diagnostic tests, therapies, and research into leukemic stem cell transplants have combined to make what was once considered a fatal, though rare, disease into a chronic, livable condition that patients learn to manage.

The Chronic Myeloid Leukemia Specialty Registry, which began accepting participants in October 2013, documents the experiences of a cross-section of people living with CML. The Chronic Myeloid Leukemia Advisory Council—made up of CML 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**).

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KEY FINDINGS

THIS REPORT CONTAINS NUMEROUS INSIGHTS
INTO THE CML EXPERIENCE. KEY FINDINGS INCLUDE:

CANCER-RELATED DISTRESS

56% ARE WORRIED ABOUT THE FUTURE AND WHAT LIES AHEAD

MONEY WORRIES AND HEALTH INSURANCE ARE A TOP CONCERN WITH **67%** OF CML PATIENTS REPORTING MODERATE TO VERY SERIOUS CONCERN

50% ARE AT RISK FOR CLINICAL DEPRESSION

ADHERENCE TO ORAL MEDICATION

20% REPORT THEY MISS A DOSE AT LEAST ONCE A MONTH

32% REPORT BELIEVING THAT IT IS OKAY TO MISS A DOSE OF CML MEDICINE EVERY NOW AND THEN

30% INDICATE THAT THEY NEVER TELL THEIR DOCTOR IF THEY MISS OR SKIP A DOSE OR DOSES OF MEDICATION

SIDE EFFECTS AND SYMPTOMS

70% SAID THAT FATIGUE INTERFERED WITH THEIR DAILY LIFE OVER THE PAST 30 DAYS

42% REPORTED THAT LOSS OF CONCENTRATION AND MEMORY INTERFERED WITH THEIR DAILY LIFE

26% BELIEVED THEIR FAMILY MEMBERS HAVE LITTLE TO NO UNDERSTANDING OF THEIR SIDE EFFECTS AND SYMPTOMS

FINANCIAL IMPACT

53% REPORT AN UNEXPECTED FINANCIAL BURDEN BECAUSE OF THE COST OF ORAL MEDICATIONS

39% REPORT SIGNIFICANT LEVELS OF INTRUSIVE THOUGHTS ABOUT THEIR ABILITY TO MANAGE THE COSTS OF CANCER CARE

27% ARE REPORTING OVER $250 IN MONTHLY OUT-OF-POCKET COSTS TO COVER CANCER CARE

Who is in the Registry?

This 2017 report analyzes survey responses from 497 CML patients who reside in the United States and completed survey questions from the opening of the Registry in October 2013 to December 31, 2016 (in the tables below, the number of responses is 497 unless otherwise noted).

FIGURE 1 **CHRONIC MYELOID LEUKEMIA SPECIALTY REGISTRY SURVEY DEMOGRAPHICS**

	NUMBER OF PARTICIPANTS (n)	*PERCENT*
AGE	(n = 362)	
Mean age	55.3 years, SD = 12.7	Range: 21 to 84
18-44	70	19%
45-64	208	58%
>=65	84	23%
GENDER	(n = 432)	
Male	142	32%
Female	289	67%
RACE	(n = 432)	
White	381	87%
NON-HISPANIC ETHNICITY	(n = 432)	
	384	89%
EDUCATION	(n = 432)	
High school or less	53	13%
Associate degree or some college	158	37%
Bachelor degree	128	30%
Graduate degree or higher	91	21%
REGION	(n = 396)	
Urban	74	19%
Suburban	213	54%
Rural	97	24%
EMPLOYMENT STATUS	(n = 390)	
Full-time	171	44%
Part-time	47	12%
Retired	85	22%
Not employed due to disability	53	13%
Not employed (reason not specified)	34	9%
ANNUAL INCOME	(n = 340)	
<$40K	85	25%
$40-59.9K	44	13%
$60-79.9K	37	10%
$80-99.9K	26	8%
$100K+	70	21%
Prefer not to share	74	22%

FIGURE 2 TIME SINCE DIAGNOSIS OF SURVEY PARTICIPANTS

	NUMBER OF PARTICIPANTS (n)	*PERCENT*
TIME SINCE DIAGNOSIS	(n = 11)	
1-1.9 years	3	27%
2–4.9 years	2	18%
>=5 years	6	55%

What are we learning?

DIAGNOSTIC EXPERIENCE

CML is a relatively rare form of leukemia. Due in part to its slow-growing nature, it is often detected late because patients may not show acute symptoms. It is not uncommon for diagnosis to occur after an annual physical or doctor's visit. Thirty-three percent of survey respondents were diagnosed from blood work after a routine checkup where they felt well. Just 20% received their diagnosis after test results from a doctor's visit due to feeling unwell or run down, and only 5% were diagnosed from test results for a fever or infection. At the time they completed the survey, 92% of respondents described their cancer as chronic.

CANCER-RELATED DISTRESS

With the advent of recent therapies, many people with CML are able to manage their disease as a chronic condition. However, they can experience high, even acute levels of stress related to their disease experience. 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.[1]

TREATMENT DECISION-MAKING AND PLANNING

Recent oral therapies have ushered in a new era for many CML patients, who are now experiencing better survival outcomes. Although slightly more than half of patients (53%) reported being very much or quite a bit involved in treatment decision-making, only 21% felt they were prepared to discuss treatment options with their doctor (Figure 4).

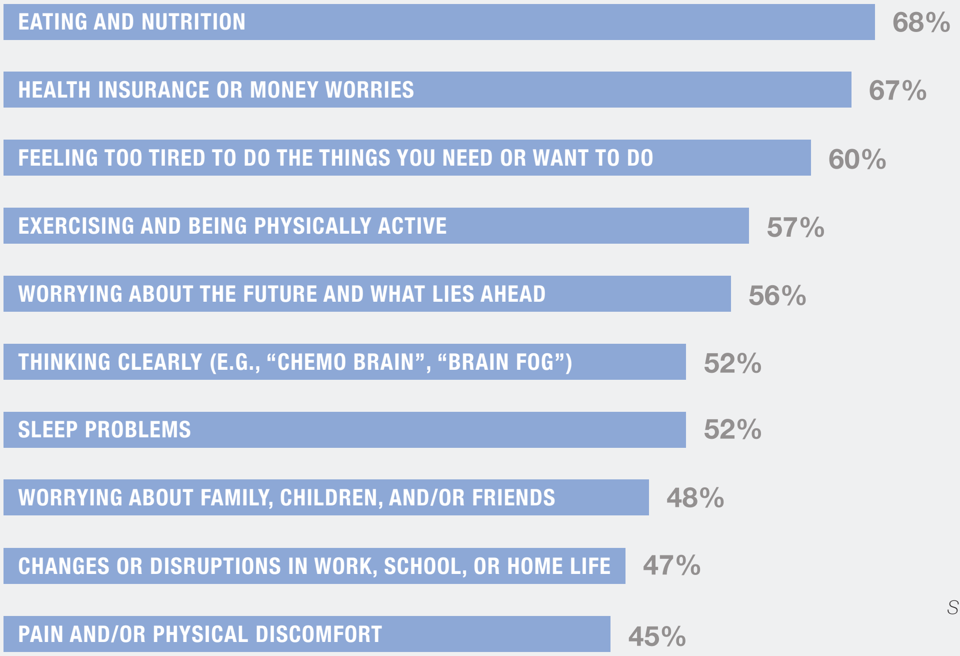
Where to seek treatment is one of the biggest decisions a cancer patient can make after receiving a diagnosis. Figure 5 illustrates how CML patients rated a number of factors influencing where they chose to seek treatment.

SIDE EFFECTS AND SYMPTOMS

CML patients often experience symptoms as chronic conditions rather than acute episodes, as the vast majority are on lifelong, daily oral medication regimens. Figure 6 shows the degree to which CML Specialty Registry respondents reported that certain side effects and symptoms interfered with—not simply affected—their day-to-day lives.

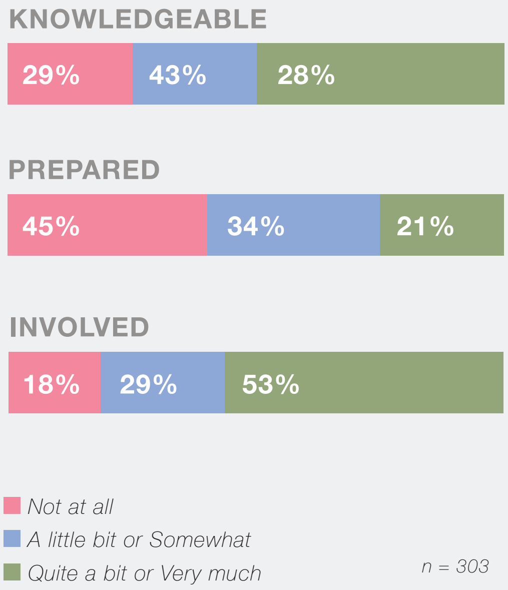
Dramatic increases in survival rates for people with CML are fairly well known, and quality of life has greatly improved on oral therapies compared with chemotherapy drugs that were once common components of many treatment plans. An overwhelming proportion of respondents (94%) reported being at least somewhat satisfied with how they are communicating with their health care

FIGURE 3 **TOP 10 CONCERNS OF CML PARTICIPANTS**

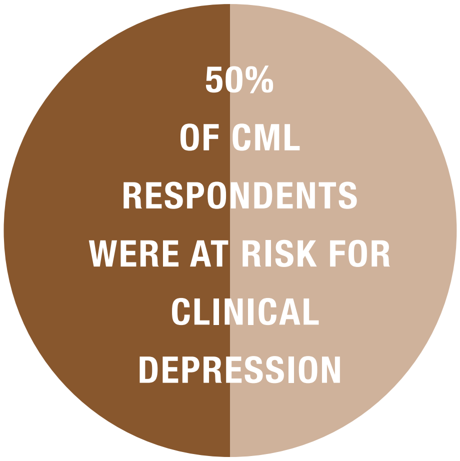


Percent of Patients Moderately to Very Seriously Concerned
n = 303

FIGURE 4 **TREATMENT DECISION-MAKING PROCESS: CML**



n = 303

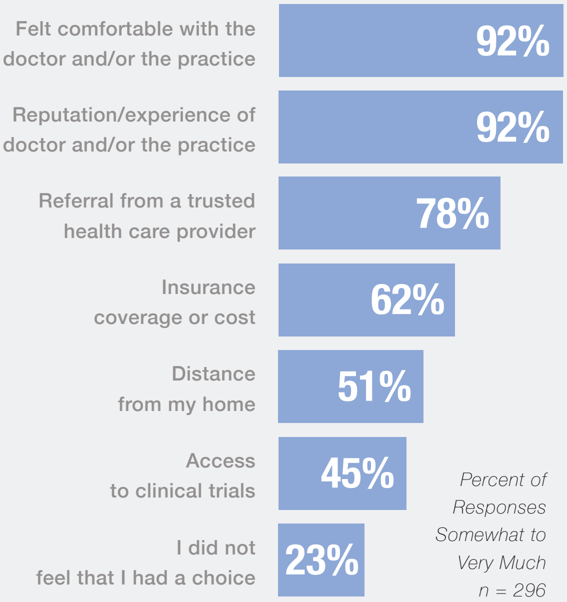


team about their side effects; 72% indicated it was "somewhat" to "very easy" to contact a team member with concerns about side effects, and 93% believed their doctor takes enough time to address these concerns. Twenty-six percent of respondents believed their family members and caregivers have little to no understanding of their side effects and symptoms, and 45% felt family and close friends had little to no idea about what it is like to live with cancer.

MULTIDISCIPLINARY TEAM TREATMENT

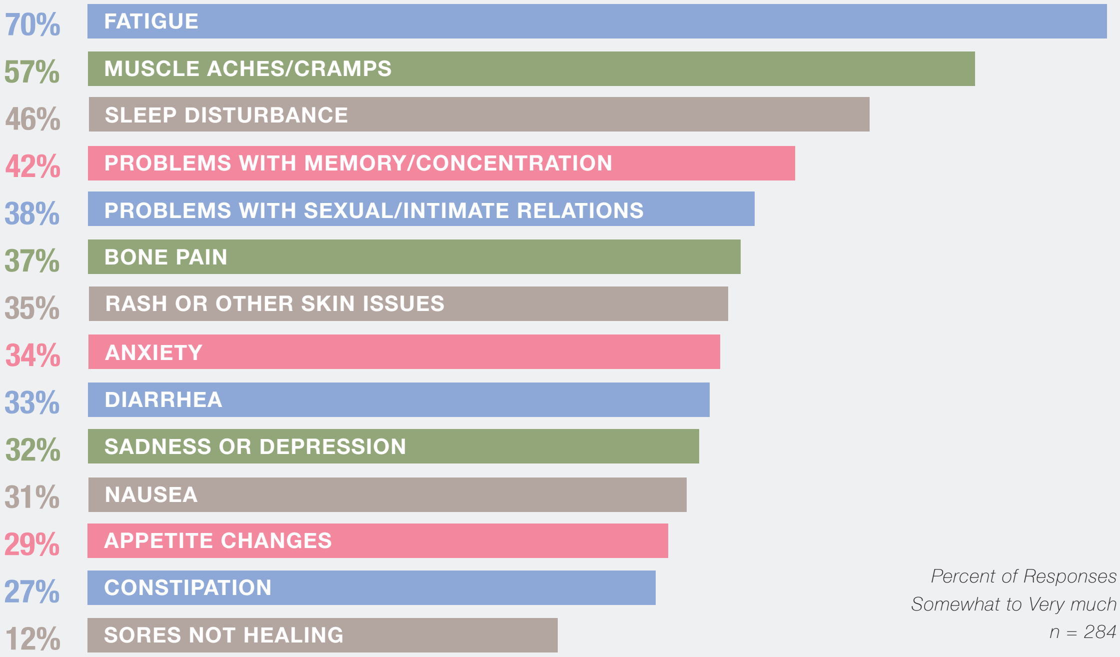
CML care teams can include an oncologist, a hematologist, a financial counselor, nurses, and social workers. Juggling appointments with and information from multiple providers can be challenging. In the survey, 79% of patients were “somewhat,” “quite a bit,” or “very much” satisfied with the coordination of their care. Respondents were split on whether they asked for a second opinion from another doctor after their initial diagnosis, with 51% seeking out a second opinion.

FIGURE 5 **FACTORS CONTRIBUTING TO CML TREATMENT AND FOLLOW-UP CARE**



Percent of Responses Somewhat to Very Much
n = 296

FIGURE 6 **CML SIDE EFFECT AND SYMPTOM INTERFERENCE IN PAST 30 DAYS**



Percent of Responses Somewhat to Very much
n = 284

DRUG ADHERENCE

CML Specialty Registry respondents have expressed challenges taking their medication as directed. Of the 95% of respondents who reported that they orally ingest medication, 24% reported they have had to change their medicine at least once, and one-fifth (20%) reported they miss a dose at least once a month. Further, if they do miss a dose, 30% indicated that they never tell their doctor. About a third (32%) of respondents reported believing that it is okay to miss a dose of CML medicine every now and then.

COST OF CARE

Even small monthly out-of-pocket costs can have an impact on survivors who may be on treatment for the rest of their lives. Insurance coverage can mask the monetary impact that patients experience on a regular basis. Many respondents were able to quantify monthly out-of-pocket costs related to their cancer (Figure 7). Not surprisingly, over half (53%) of CML respondents indicated that these out-of-pocket costs "somewhat" to "very much" affect their household. Thirty-nine percent of CML respondents reported significant levels of intrusive thoughts about their ability to manage costs of their cancer care, according to the Impact of Events Scale.[3] A majority (83%) of respondents had discussed costs with a member of their health care team. In addition to out-of-pocket costs, cancer patients often struggle paying for costs they never anticipated when they were first diagnosed or began treatment. Figure 8 demonstrates respondents' burden of frequent unexpected costs.

FIGURE 7 **CML MONTHLY OUT-OF-POCKET COSTS**

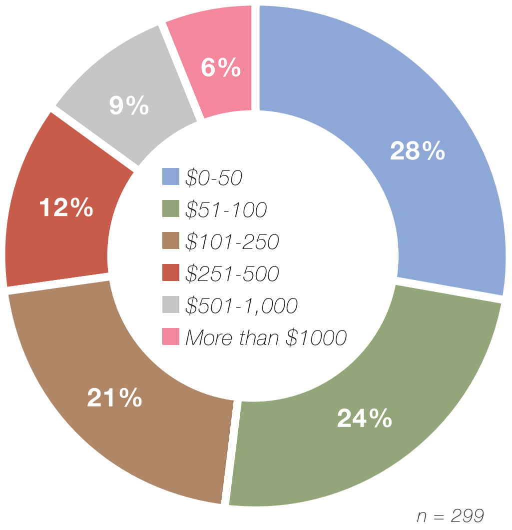
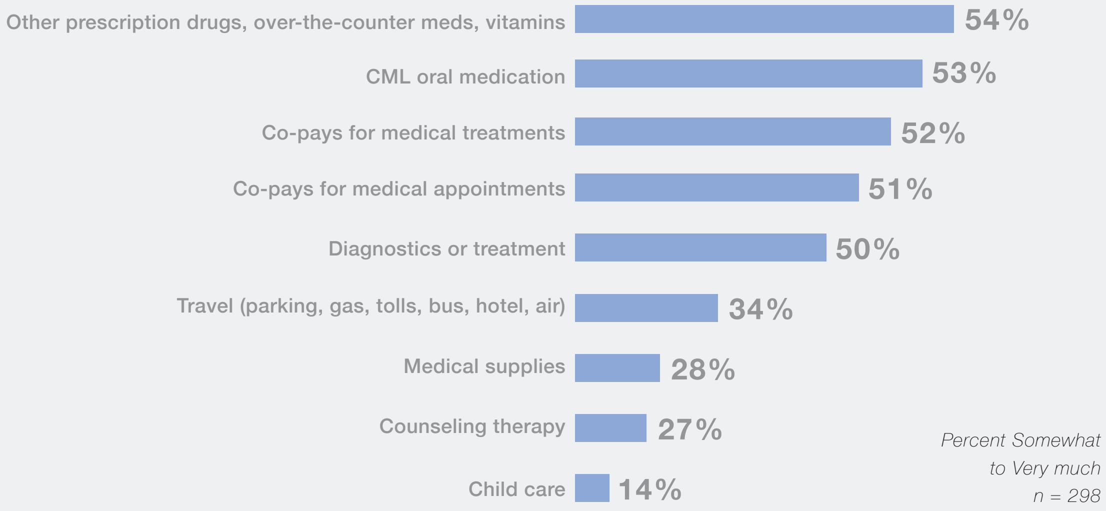


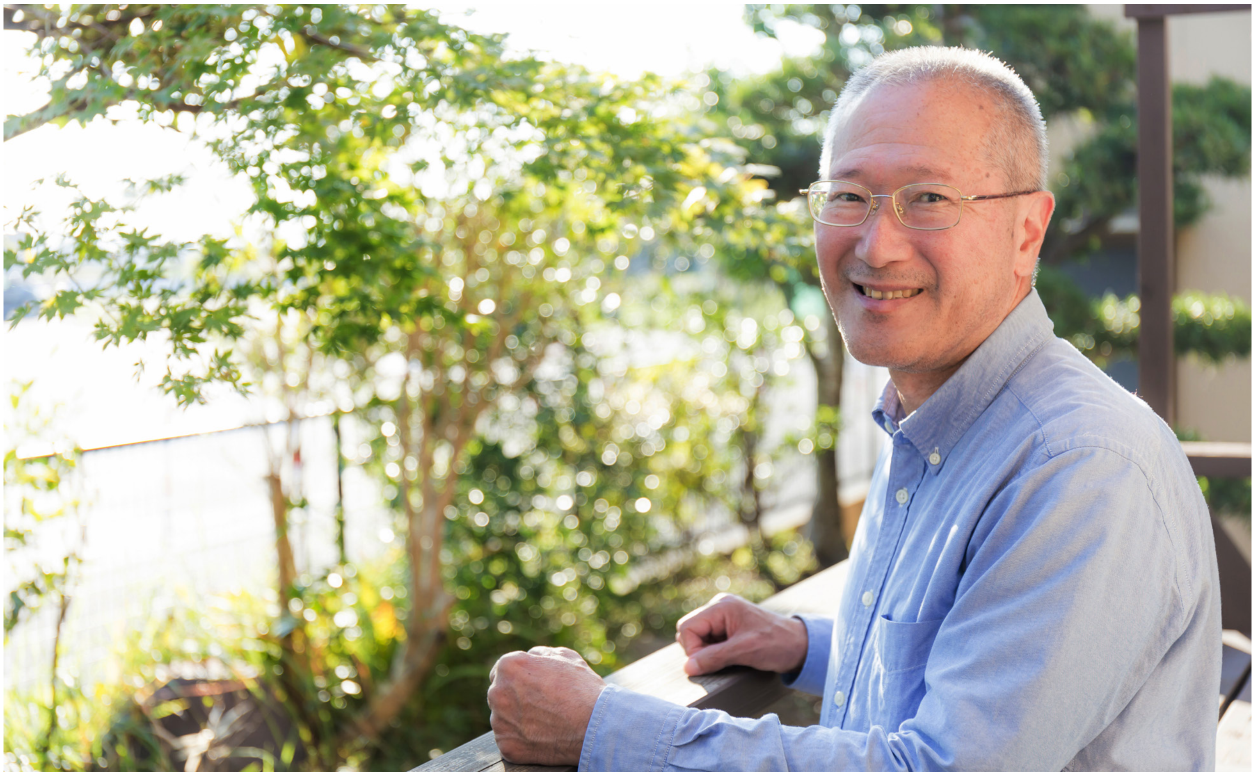
FIGURE 8 **BURDEN OF UNEXPECTED COSTS ASSOCIATED WITH CML**



Learn More

For more information and to see our other specialty reports please visit:
www.cancersupportcommunity.org/RegistryIndexReport2017

- Breast Cancer Specialty Registry Report
- Caregiver Specialty Registry Report
- Chronic Lymphocytic Leukemia (CLL) 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
- Stomach 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.

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