

Multiple Myeloma Specialty Registry Report 2017

What is the Multiple Myeloma Specialty Registry?





Multiple myeloma is a relatively rare cancer of the blood plasma cells, with approximately 30,000 new diagnoses expected in the United States in 2017 (American Cancer Society, 2016).

The Multiple Myeloma Specialty Registry, which began accepting participants in June 2013, documents the experiences of a cross-section of people living with multiple myeloma. The Multiple Myeloma Advisory Council—made up of multiple myeloma 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).



KEY FINDINGS

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

 <p>QUALITY OF LIFE</p>	<p>33% OF SURVIVORS RATE THEIR OVERALL HEALTH AS VERY GOOD OR EXCELLENT</p> <p>59% ARE CONCERNED ABOUT REMAINING PHYSICALLY ACTIVE</p> <p>56% ARE CONCERNED ABOUT MOVING AROUND (CLIMBING STAIRS, LIFTING)</p> <p>42% ARE AT RISK FOR CLINICAL DEPRESSION</p>
 <p>SOCIAL AND WORK IMPACT</p>	<p>42% ARE RELUCTANT TO ASK FOR HELP</p> <p>40% HAVE FORGONE JOB OPPORTUNITIES OR CAREER ADVANCEMENT</p> <p>30-40% HAVE LIMITED CONTACT WITH FAMILY OR FRIENDS</p>
 <p>SIDE EFFECT IMPACT AND MANAGEMENT</p>	<p>64% SAY THAT FATIGUE INTERFERES WITH THEIR DAILY LIFE</p> <p>34% REPORT SUBSTANTIALLY WORSE FATIGUE THAN THE NATIONAL AVERAGE</p> <p>11% NEVER OR RARELY INFORM THEIR HEALTH CARE TEAM OF THE FULL EFFECTS OF THEIR SIDE EFFECTS AND SYMPTOMS, AND</p> <p>23% ONLY SOMETIMES REPORT THESE SYMPTOMS</p>
 <p>FINANCIAL IMPACT</p>	<p>38% DID NOT TALK ABOUT COSTS OF TREATMENT WITH A MEMBER OF THE HEALTH CARE TEAM</p> <p>84% BELIEVE FINANCIAL COUNSELING WOULD BE HELPFUL TO MANAGE THE COSTS OF LIVING WITH MULTIPLE MYELOMA</p> <p>34% REPORT SIGNIFICANT LEVELS OF INTRUSIVE THOUGHTS ABOUT THEIR ABILITY TO MANAGE THE COSTS OF THEIR CANCER</p>

Who is in the Registry?

This 2017 report presents analysis from 598 multiple myeloma patients who reside in the United States and completed survey questions from the opening of the Registry in June 2013 through December 31, 2016 (in the tables below, the number of responses is 598 unless otherwise noted).

FIGURE 1 MULTIPLE MYELOMA SPECIALTY REGISTRY SURVEY DEMOGRAPHICS		
	NUMBER OF PARTICIPANTS (n)	PERCENT
AGE (n = 400)		
Mean age	62 years, SD = 9.5	Range: 26 to 88
18-44	16	4%
45-64	229	57%
>=65	155	39%
GENDER (n = 435)		
Male	188	43%
Female	247	57%
RACE (n = 435)		
White	370	85%
Black or African American	43	10%
NON-HISPANIC ETHNICITY (n = 435)		
	393	90%
EDUCATION (n = 435)		
High school or less	54	13%
Associate degree or some college	129	29%
Bachelor degree	135	31%
Graduate degree or higher	111	26%
REGION (n = 416)		
Urban	86	21%
Suburban	226	54%
Rural	94	23%
EMPLOYMENT STATUS (n = 410)		
Full-time	88	21%
Part-time	26	6%
Retired	171	42%
Not employed due to disability	105	26%
Not employed (reason not specified)	20	5%
ANNUAL INCOME (n = 356)		
<\$40K	93	26%
\$40-59.9K	57	16%
\$60-79.9K	35	10%
\$80-99.9K	32	9%
\$100K+	47	13%
Prefer not to share	88	25%

FIGURE 2 TIME SINCE DIAGNOSIS OF SURVEY PARTICIPANTS

	NUMBER OF PARTICIPANTS (n)	PERCENT
TIME FROM DIAGNOSIS	(n = 291)	
<1 year	18	6%
1-1.9 years	54	19%
2-4.9 years	114	39%
>=5 years	105	36%

Depending on their form and stage of myeloma, patients may undergo radiation therapy, surgery, and chemotherapy, which may be followed by a stem cell transplant. In addition to the medical background information outlined in Figure 2, 69% of respondents reported they had received at least one autologous (using their own stem cells) blood and bone marrow transplant. Only 5% had received an allogeneic (using donor stem cells) transplant.

What are we learning?

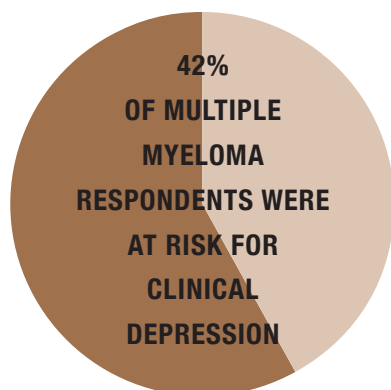
PERCEPTIONS ABOUT HEALTH

Overall, one-third (33%) of multiple myeloma patients described their overall health as excellent or very good, while 42% reported fair or poor health (Figure 3).

CANCER-RELATED DISTRESS

Living with multiple myeloma can be challenging, especially as people are living longer with the disease. Figure 4 presents the 10 items that most respondents were moderately, seriously, or very seriously concerned about according to CancerSupportSource[®], a validated distress screening instrument.¹

CancerSupportSource features a depression subscale, which demonstrated that 42% of multiple myeloma respondents were at risk for clinical depression.



While psychosocial needs are of great concern to a health care team, 81% of multiple myeloma respondents would discuss emotional concerns during a doctor visit only if the doctor raised them. Fewer than 9% would bring up emotional concerns on their own, and 10% said they would never discuss them during a doctor visit.

QUALITY OF LIFE

Multiple myeloma patients rate quality of life as one of the most important factors when making decisions about their cancer care. The Multiple Myeloma Specialty Registry incorporates the PROMIS-29, which compares how patients describe their quality of life to other U.S. population groups across different areas of life.²

FIGURE 3 SURVEY PARTICIPANTS' PERCEIVED OVERALL HEALTH

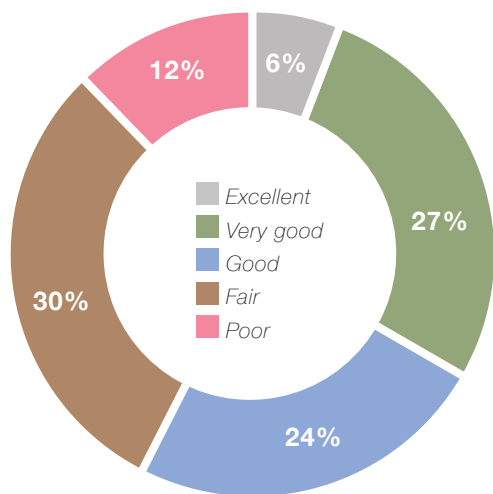
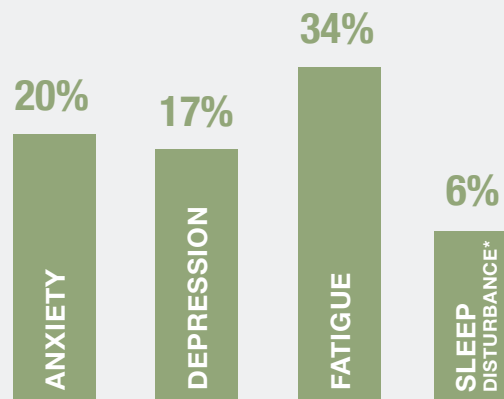


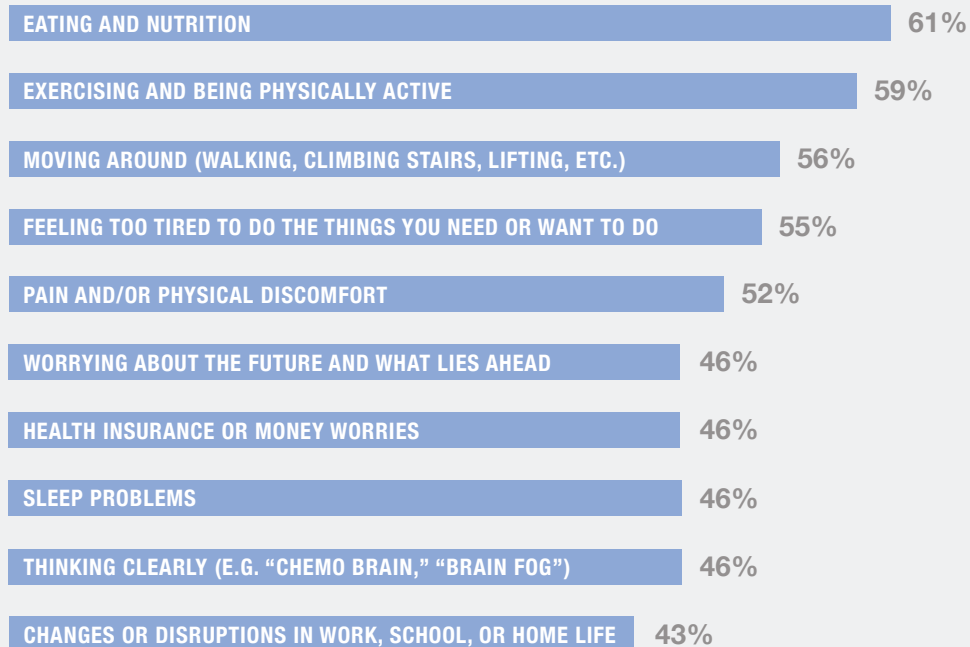
FIGURE 5 PERCENT OF MULTIPLE MYELOMA SURVIVORS REPORTING WORSE QUALITY OF LIFE



Note: All comparisons are vs. general U.S. population, except where * denotes comparison to U.S. population group balanced to include more people with chronic illness. Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than the respective comparison group.

n = 285

FIGURE 4 TOP 10 CONCERNS OF MULTIPLE MYELOMA PARTICIPANTS



Percent of Patients Moderately to Very Seriously Concerned

n = 598

As Figure 5 illustrates, many multiple myeloma patients reported substantially worse quality of life than the national average for fatigue (34%), anxiety (20%), depression (17%) and sleep disturbance (6%).

Multiple myeloma can impact many aspects of life, including personal relationships and work opportunities. Figure 6 delineates the social impact of multiple myeloma.

SIDE EFFECTS AND SYMPTOMS

People with multiple myeloma often undergo intensive chemotherapeutic regimens that can

result in significant physical and emotional side effects. Figure 7 shows the frequency with which respondents experienced common side effects during the past seven days prior to completing the survey.

In addition to the frequency of side effects, multiple myeloma respondents also rated the degree to which side effects impacted their lives in the past seven days (Figure 8).

Communicating about side effects to the health care team is important for effective care. Eleven percent of survey respondents never or rarely inform their care team of the full effects of their side effects and symptoms, and 23% only sometimes report these symptoms (Figure 9).

Forty-one percent of multiple myeloma respondents revealed that, at least sometimes, side effects impact whether or not they choose a treatment option. In addition, 20% believed that their care team “not at all” to “somewhat” understood their side effects or symptoms.

TREATMENT DECISION-MAKING AND PLANNING

Recent therapeutic advancements for multiple myeloma have led to more complex treatment decisions for patients. Although patients are very involved in treatment decision-making, they are far less likely to report feeling knowledgeable about treatment options or prepared to discuss treatment options with their doctor (Figure 10).

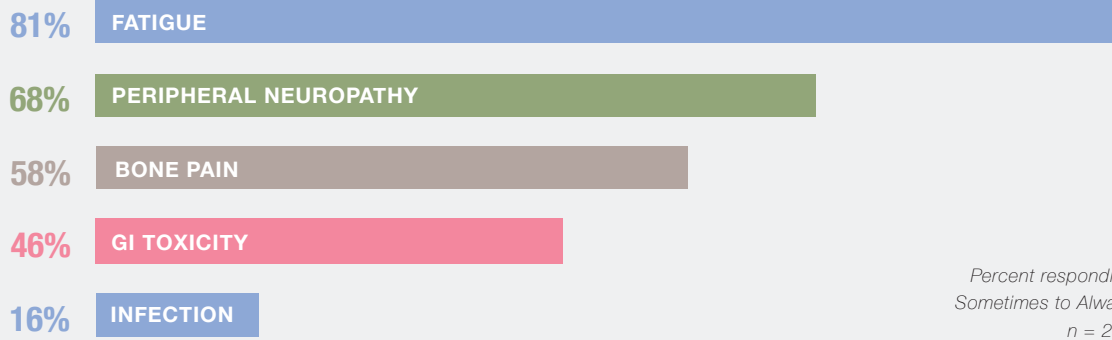
Given the rapidly changing landscape in treatment, choice in provider can be important to multiple myeloma survivors. Overall, 84% of respondents to the survey felt that they had a choice in where to receive treatment. Factors that had “quite a bit” or “very much” impact on where survivors seek treatment and follow-up care included access to a multiple myeloma specialist (79% of respondents) and trust in their doctor (60% of respondents). In contrast, only 26% reported that access to a clinical trial had a large impact on their decision about where to seek treatment (Figure 11).

COST OF CARE

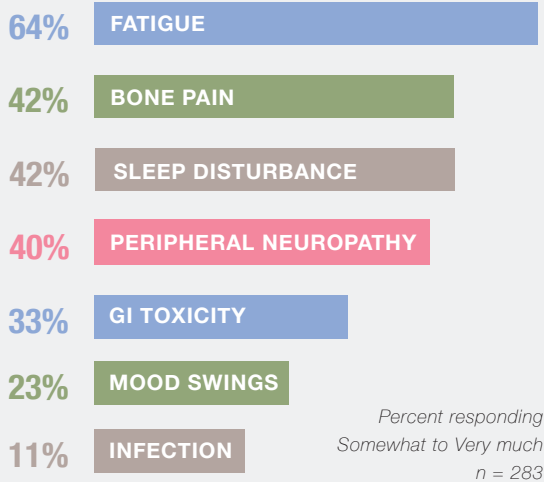
Care costs have an impact on all patients, regardless of their disease type. Thirty-four percent of multiple



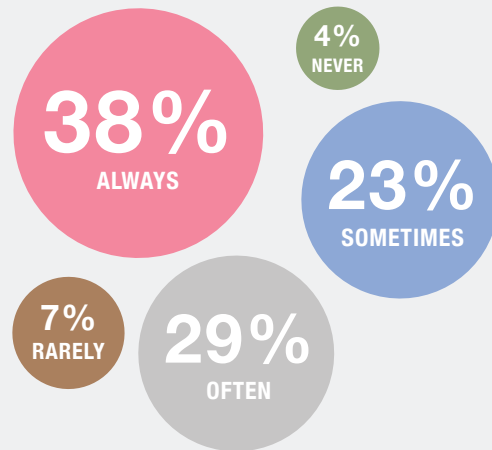
**FIGURE 7 COMMON MULTIPLE MYELOMA
SIDE EFFECTS EXPERIENCED IN PAST SEVEN DAYS**



**FIGURE 8 INTERFERENCE OF COMMON
MULTIPLE MYELOMA SIDE EFFECTS
WITH DAILY LIFE**



**FIGURE 9 FREQUENCY OF
COMMUNICATING MULTIPLE MYELOMA
SIDE EFFECTS TO HEALTH CARE TEAM**



Fear of Infection

Multiple myeloma patients are susceptible to infection. Forty-two percent of respondents reported at least one infection that required a hospital stay since their diagnosis; 10% reported three or more infections. In addition, 54% described themselves as somewhat, quite a bit, or very much afraid of getting an infection.

myeloma respondents reported significant levels of intrusive thoughts about their ability to manage the costs of their cancer care, according to the Impact of Events Scale.³ However, 38% of respondents had not discussed costs with their health care team.

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 12).

As treatment advances prolong lives of survivors, many multiple myeloma patients may see their overall cost of care increase. A large majority (84%) of survey respondents believed that financial counseling would be helpful to someone living with multiple myeloma. Roughly 75% reported they would be quite a bit or very much willing to receive financial assistance for the cost of treatment, and even more people (79%) were interested in financial assistance for their medications.

FIGURE 10 TREATMENT DECISION-MAKING PROCESS: MULTIPLE MYELOMA

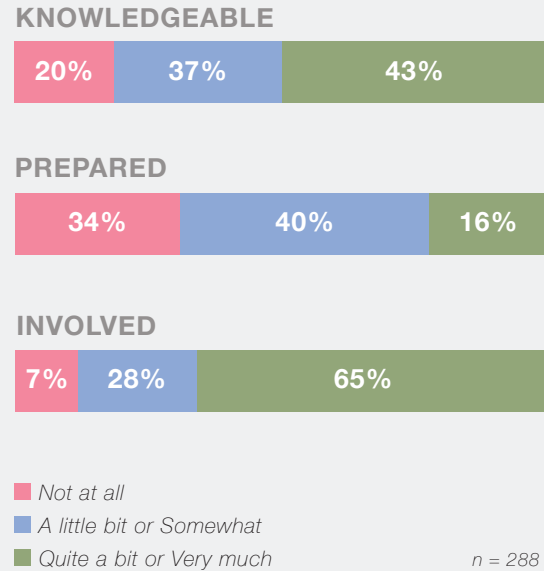
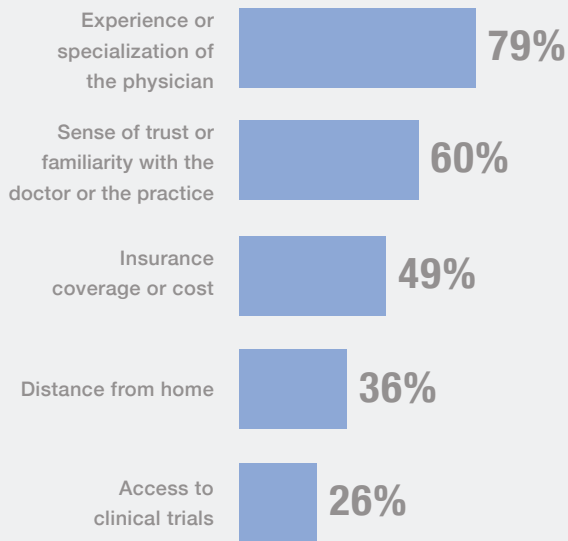
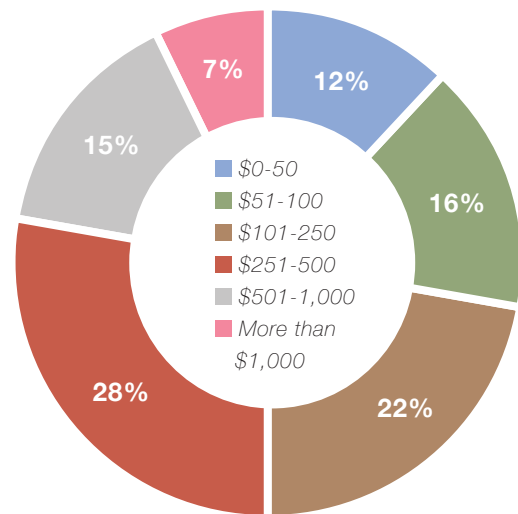


FIGURE 11 FACTORS IMPACTING WHERE MULTIPLE MYELOMA PATIENTS SEEK TREATMENT



Percentage of respondents indicating Quite a bit to Very much *n* = 284

FIGURE 12 MULTIPLE MYELOMA MONTHLY OUT-OF-POCKET COSTS



n = 288



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
- 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
- Prostate Cancer Specialty Registry Report
- Stomach Cancer Specialty Registry Report



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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

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