



Symptom Burden and Palliative Care for Multiple Myeloma Patients: Cancer Experience Registry Findings

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Introduction

Multiple myeloma (MM) patients are living longer given treatment advances in recent years. Yet, these patients remain challenged by disease complications and adverse treatment effects. Concurrent oncology/palliative care can relieve symptom burden and improve quality of life for cancer patients, but the benefits of concurrent care for MM patients is not well described.

Objective

Our objective was to study symptoms and adverse effects experienced by MM patients and communication patterns with their health care teams (HCTs).

Method

- The data source for this study is the Cancer Support Community's (CSC) Cancer Experience Registry: MM. From July 2013-2014, CSC registered 495 MM patients to the Cancer Experience Registry: MM.
- Registrants were recruited through CSC and other community networks, including The Leukemia & Lymphoma Society.
- 331 US-based registrants completed surveys about their MM history, symptoms and communication with their HCT.
 - We assessed distress using the CancerSupportSource® distress screening tool (Miller et al., 2012).
 - To determine symptom interference with daily life, we asked patients: "In the past 7 days, how much did the following side effects and symptoms interfere with your daily life?" (1: Not at all – 5: Very much). Patients were also asked about steroid use for MM management and steroid-specific side effects.
 - We also asked about patient report of symptoms to the HCT.

Results

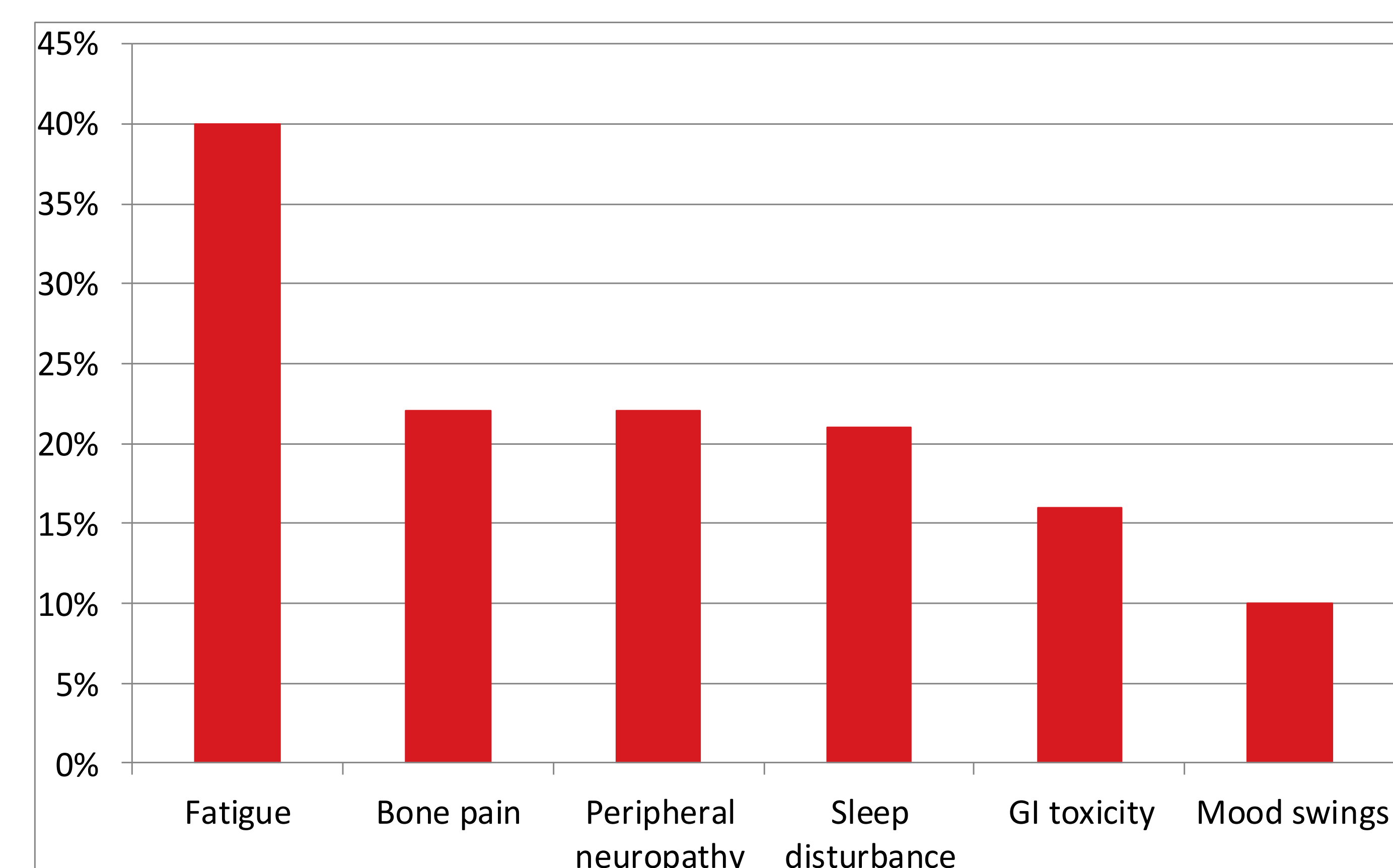
Table 1. Patient Characteristics (n=331)

Characteristic	%
Female	53
College degree or higher	56
Income < \$40K	35
Relapse	40
Currently receiving treatment	73
Age (median)	64 years
Time since MM diagnosis (median)	4.5 years

Results

Symptom Interference with Daily Living

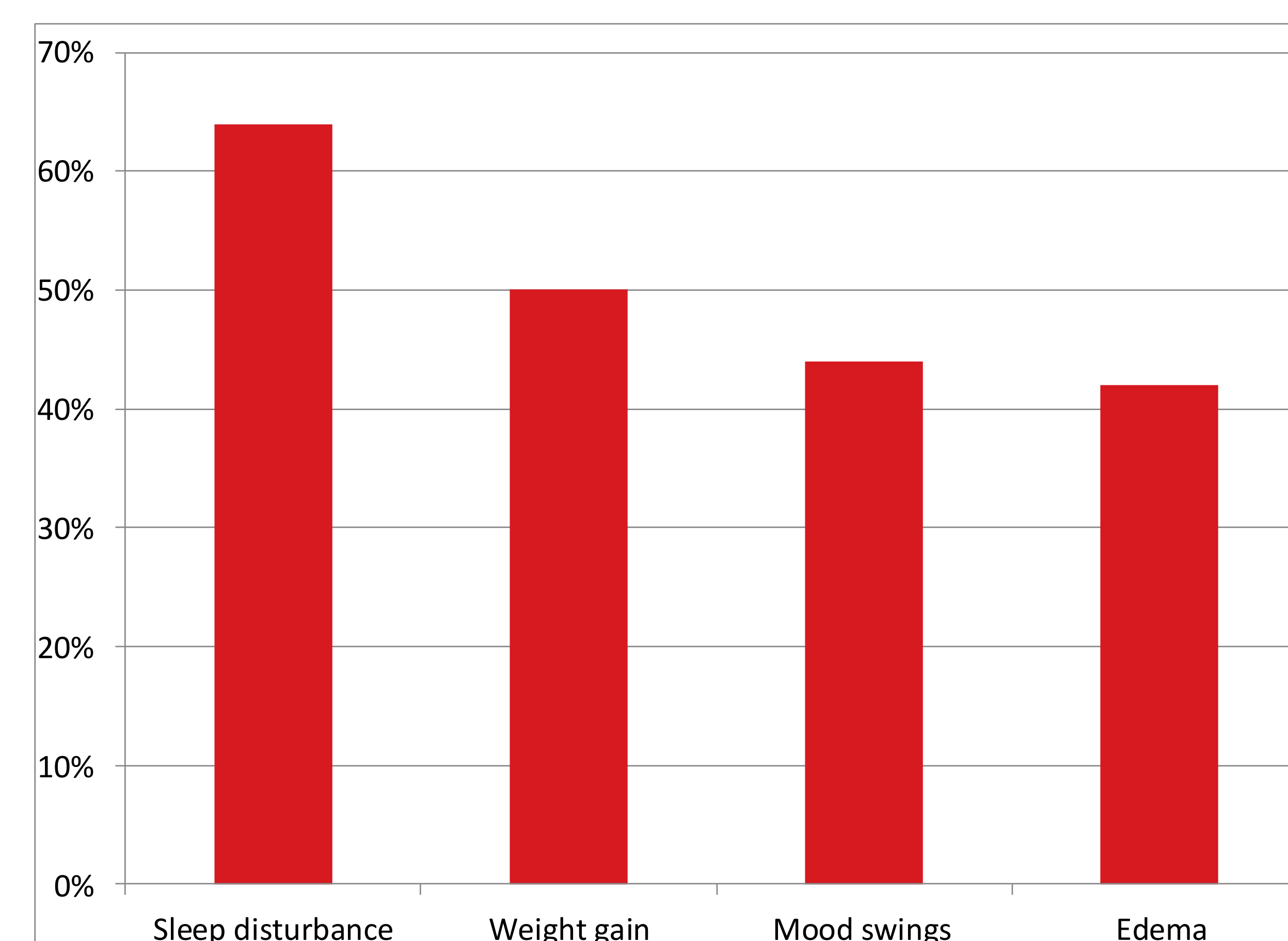
Figure 1. Percent indicating symptoms interfering "quite a bit" or "very much" with daily living.



In multivariate analysis, the daily effects of fatigue, pain, sleep disturbance and mood swings were independently associated (p<0.05) with distress.

Steroid-related Adverse Effects

Figure 2. Percent indicating adverse effects related to steroids for MM management (n=282)



Results

Communication with Health Care Team about Symptoms or Adverse Effects

- 36% did not report all symptoms and adverse effects to their HCTs. The most common reason was, "I don't think anything can be done about these problems."
- One-third (34%) reported their HCT never told them steroids could cause adverse effects.
- 85% felt their HCT prepared them (somewhat, quite a bit, or very much) to manage adverse effects of MM treatment, yet half (50%) felt little or no control over the physical side effects of MM and its treatment.

Conclusion

- A high proportion of participating MM patients indicated that symptoms have a major impact on their daily quality of life. Yet, 36% did not report all symptoms or adverse effects to their HCTs.
- Many symptoms are amenable to interventions by palliative care specialists, which may improve MM patients' quality of life.
- These findings support the integration of palliative care services throughout the continuum of care for persons with MM.

Acknowledgements

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Reference

Miller, M., Mullins, C., Onukwugha, E., Golant, M., & Buzaglo, J. (2014). Discriminatory power of a 25-item distress screening tool: a cross-sectional survey of 251 cancer survivors. *Qual Life Res*, 23 (10): 2855-2863.



The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers.

- The Registry is for all cancer survivors and caregivers, but also includes 11 disease specific surveys including MM.
- Findings contribute toward advancing research, health care and policy.
- Over 8,270 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org