



CANCER EXPERIENCE REGISTRY.

A PROGRAM *of the* CANCER SUPPORT COMMUNITY 

Multiple Myeloma Patient Experience with Financial Toxicity

Findings from the Cancer Experience Registry

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Background

- In the context of rising costs of health care, patients are having to assume more costs
- Patients have to assume both direct (co-pays, Rx) and indirect (transportation, loss of income) costs
- People living with MM may have to manage a significant financial burden related to care
- Financial toxicity is associated with reduced quality of life and poorer health outcomes
- **Aim: To describe financial distress among MM patients and communication about cost of care with health care team.**

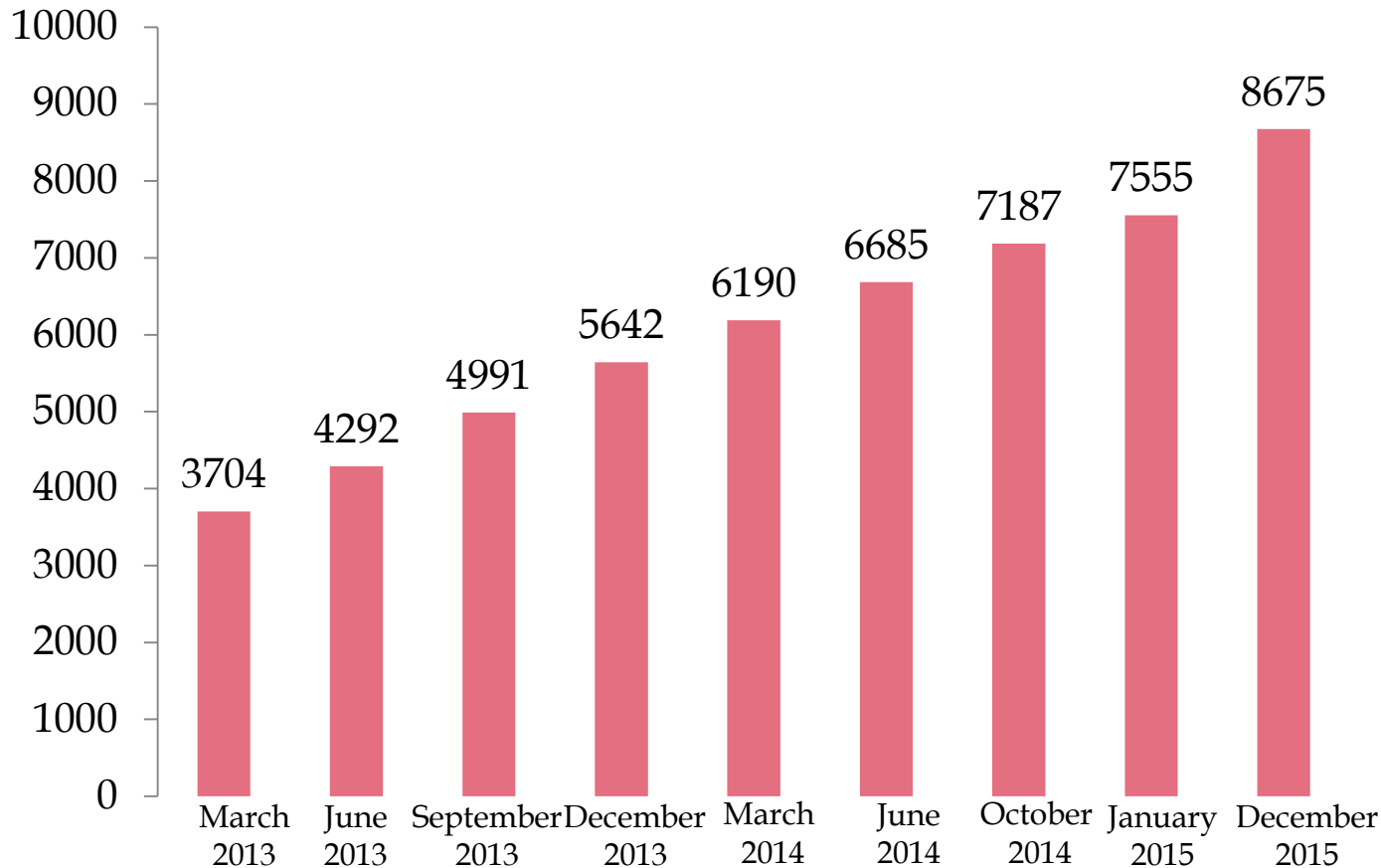


CANCER EXPERIENCE REGISTRYSM

- Tracks the social and emotional experience of cancer patients and survivors across the US
- Engages them to share their voices about issues that matter to them
- Provides a dynamic learning environment for patients, researchers, and other key stakeholders
- Connects an expanding number of registries



The Evolving Registry



40 + cancer types currently represented in the Registry:

- Breast: 4,537
- Metastatic Breast: 1,085
- **Multiple Myeloma: 548**
- CML: 540
- Lung: 138
- Prostate: 106
- Melanoma: 70
- CLL: 181
- Gastric/Stomach: 15
- Caregivers: 157

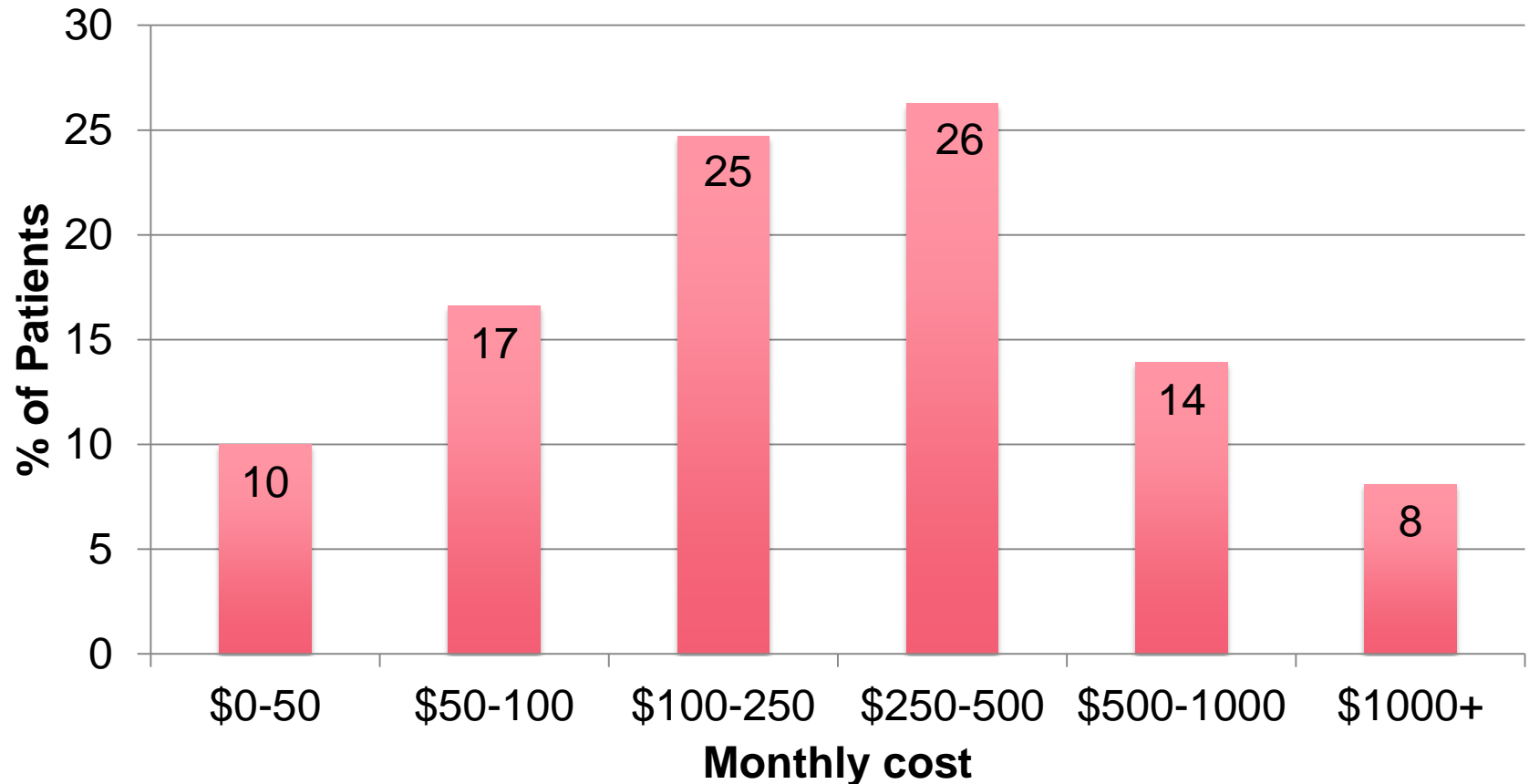
Methods

- From July 2013-July 2014, a total of 266 US-based registrants completed survey questions:
 - Financial burden of MM and its treatment
 - 27 cancer-related distress items (0 “not at all” to 4 “very seriously concerned”)
 - 4-item depression subscale (≥ 5 at risk for depression)
 - Stress-related thoughts about managing the financial impact of MM measured using the Impact of Event Scale
 - Communication about cost with health care team
- Descriptive and regression analyses

Sample characteristics (n=266)

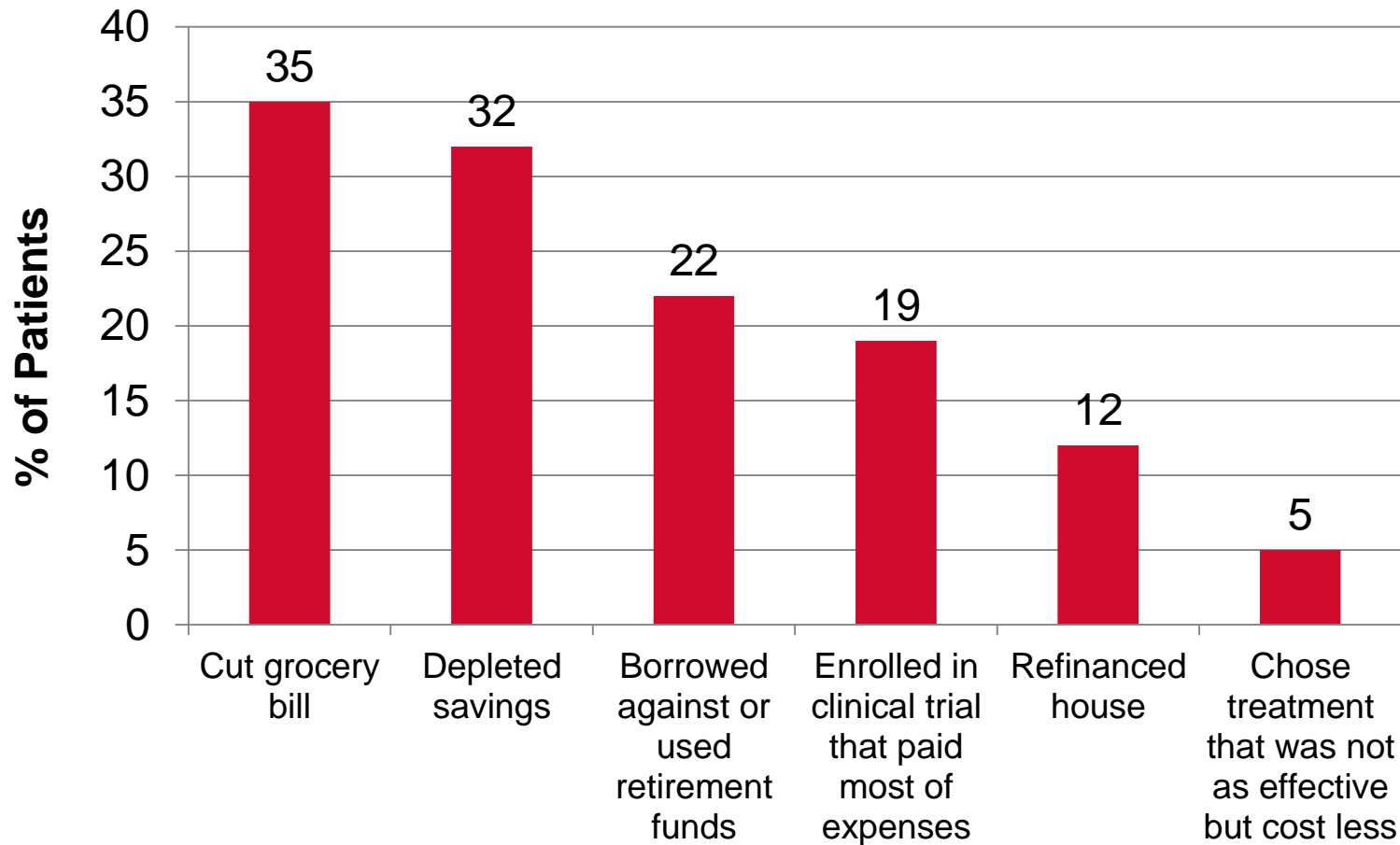
Median age	64 years
Female gender	52%
Race	
White	91%
Black	7%
Income	
<\$40	35%
Education	
At least college degree	58%
Median time since dx	4.5 years

Patient monthly out-of-pocket costs for MM



n=259

Due to the medical costs of MM



High emotional burden is associated with financial toxicity

- 47% were moderately, seriously or very seriously concerned about health insurance or money worries
- 33% reported they were often or always upset about money and the cost of care
- 32% of participants report experiencing clinically significant stress-related anxiety (intrusive ideation) about the financial cost of MM and its treatment

Increased out-of-pocket expenses are associated with greater distress

Monthly out-of-pocket costs	n	Risk for depression	Mean overall distress score
\$0-50	27	23%	26.1
\$50-100	43	33%	28.3
\$100-250	64	45%	32.7
\$250-500	68	49%	36.3
\$500-1000	36	50%	35.5
\$1000+	21	29%	29.4

Financial burden is associated with distress

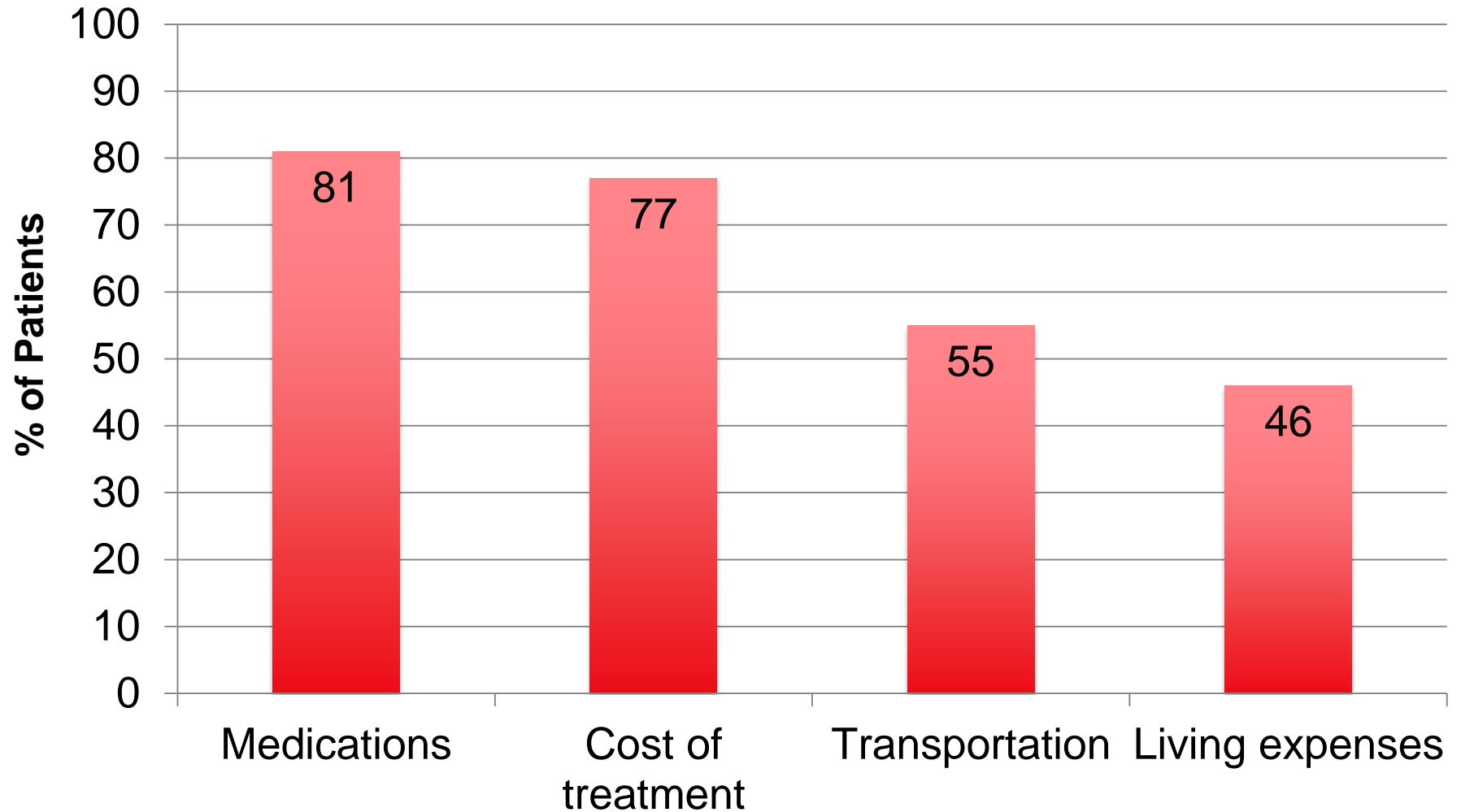
Financial burden*	n	Risk for depression	Mean overall distress score
Yes	95	58%	40.6
No	171	33%	27.7

- Patients experiencing financial burden are 2 1/2 times more likely to be at risk for depression, holding income constant [OR comparing financial burden and risk for depression is 2.56 (95% CI 1.48, 4.4)]
- *Financial burden is defined as having depleted savings or borrowed against or used money from retirement.

Patients want financial counseling

- Only 28% reported their health care team discussed the impact of MM on personal finances.
- Yet, 82% reported financial counseling would be “quite a bit” or “very much” helpful to someone with MM

Patients are willing to get financial assistance



Conclusions

- People with MM are making significant lifestyle trade-offs in order to manage the cost of health care
- A significant proportion of patients are experiencing significant levels of emotional burden related to financial toxicity
- People with financial burden are almost two and a half times more likely to be at risk for depression compared to those without financial burden
- Patients want financial counseling and are willing to get help
- We need to ensure that patients have access to appropriate financial counseling and emotional/social support and that these services are adequately reimbursed and available in the community

Thank you

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Any questions or comments

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