

Physical, Mental and Social Health among Multiple Myeloma Patients and Perceived Control Over the Course of Cancer



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Background

The US prevalence of multiple myeloma (MM) was estimated at 83,118 in 2011 and 26,850 new MM cases are projected for 2015. With advances in treatment, patients with MM are living longer. However, patients face uncertainty with the possibility of relapse or multiple relapses. The psychosocial impact of this disease and its uncertain course is not well characterized. Further, little is known about the factors that might heighten or diminish adverse social or emotional experiences among patients with MM. Guided by the Health Belief Model, a patient's perceived control over the course of MM might be an important factor in their social and emotional outcomes. We hypothesized that less perceived control over their MM would be associated with poorer psychosocial outcomes.

Objective

The purpose of this research was to:

- 1) Characterize the physical, mental and social health of patients with MM
- 2) Examine the relationship between perceived control over the course of MM and physical, mental and social health outcomes among patients with MM

Methods

- The Cancer Support Community's (CSC) Cancer Experience Registry: Multiple Myeloma is an online research initiative to investigate and raise awareness about the social and emotional experiences of patients with MM
- From July 2013 to July 2014 495 people living with MM registered for the Cancer Experience Registry: Multiple Myeloma
- Registrants were recruited through an outreach plan that included communication from CSC affiliates and other advocacy organizations
- Registrants were asked to complete an online survey that included questions about demographics, social and emotional outcomes, and perceived control over the course of MM
- Participants were asked about their perceived level of control over their MM (e.g., whether your MM will come back, get worse, or you will develop a different type of cancer)
- The PROMIS-29 (v 2.0; Beaumont et al., 2012) was used to measure physical, mental and social health. The PROMIS domains include:
 - Physical function
 - Anxiety
 - Depression
 - Fatigue
 - Sleep disturbance
 - Satisfaction with participation in social roles
 - Pain interference



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 9 disease specific surveys including one for MM.

- Patients and caregivers share their social and emotional experiences of cancer
- Data is analyzed and disseminated toward the goal of improving the lives of those experiencing cancer
- Findings contribute toward advancing research, care and policy

Over 7,600 cancer survivors and caregivers are currently registered in the Cancer Experience Registry

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

Patient Characteristics

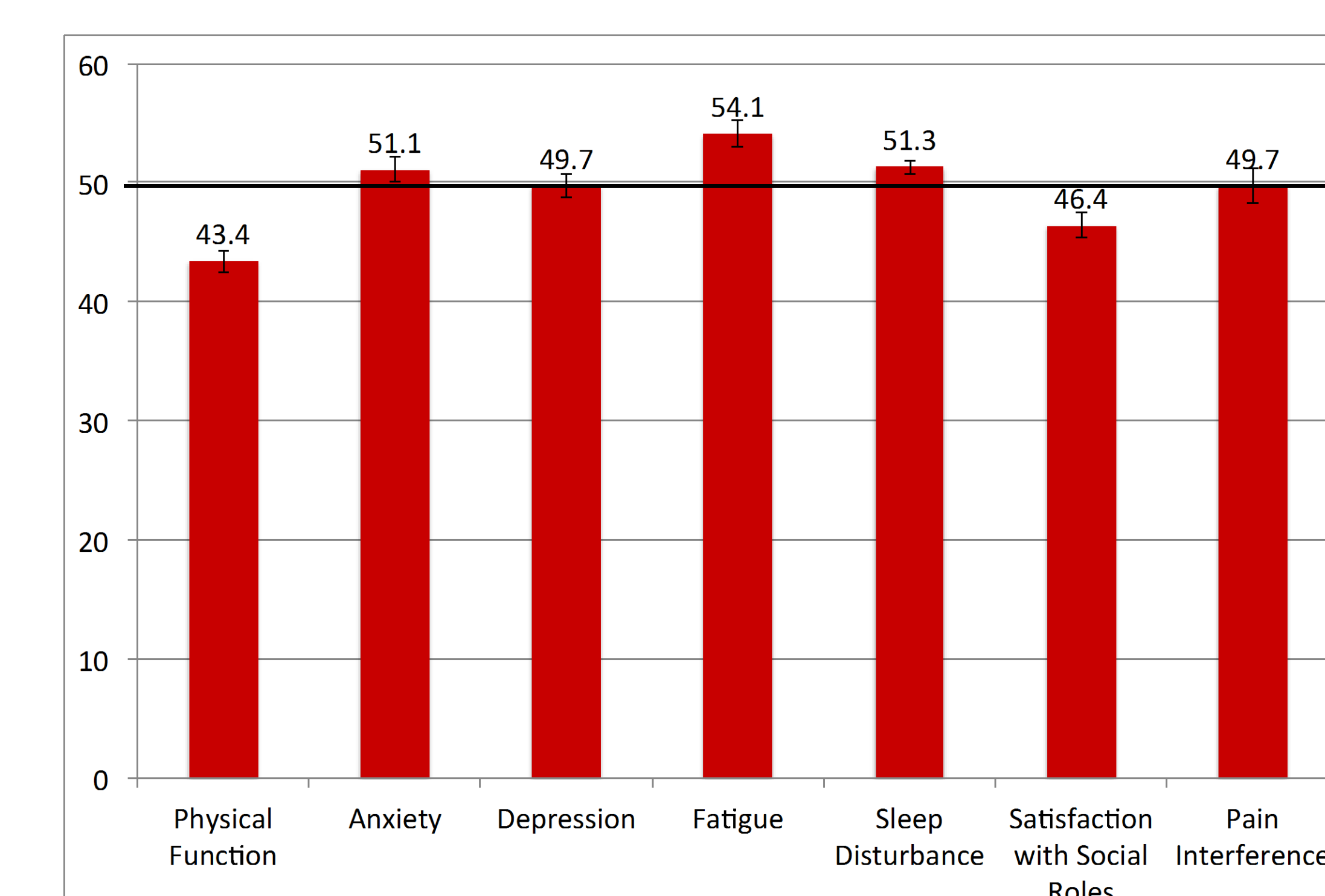
387 (78%) MM registrants responded to the survey

The analysis was limited to 365 US based registrants

- Median age: 64 years
- 54% female
- 87% Caucasian, 9.5% African American
- 35% income <40K, 30% ≥80K
- Median time since diagnosis was 4.5 years
- 48% had stage III MM
- 40% had experienced a relapse

Results

Physical, Mental and Social Health



Compared to US general population (mean=50, SD=10), PROMIS scores were significantly lower for MM survivors in physical function and satisfaction with participation in social roles; significantly higher in fatigue and sleep disturbance. They did not differ in levels of anxiety, depression, and pain interference.

Figure 1. PROMIS scores (mean with 95% CI) for MM survivors

Perceived Control

Half of MM survivors felt they had "no control at all" over the course of their MM (that is, whether their MM will come back, get worse, or they will develop a different type of cancer).

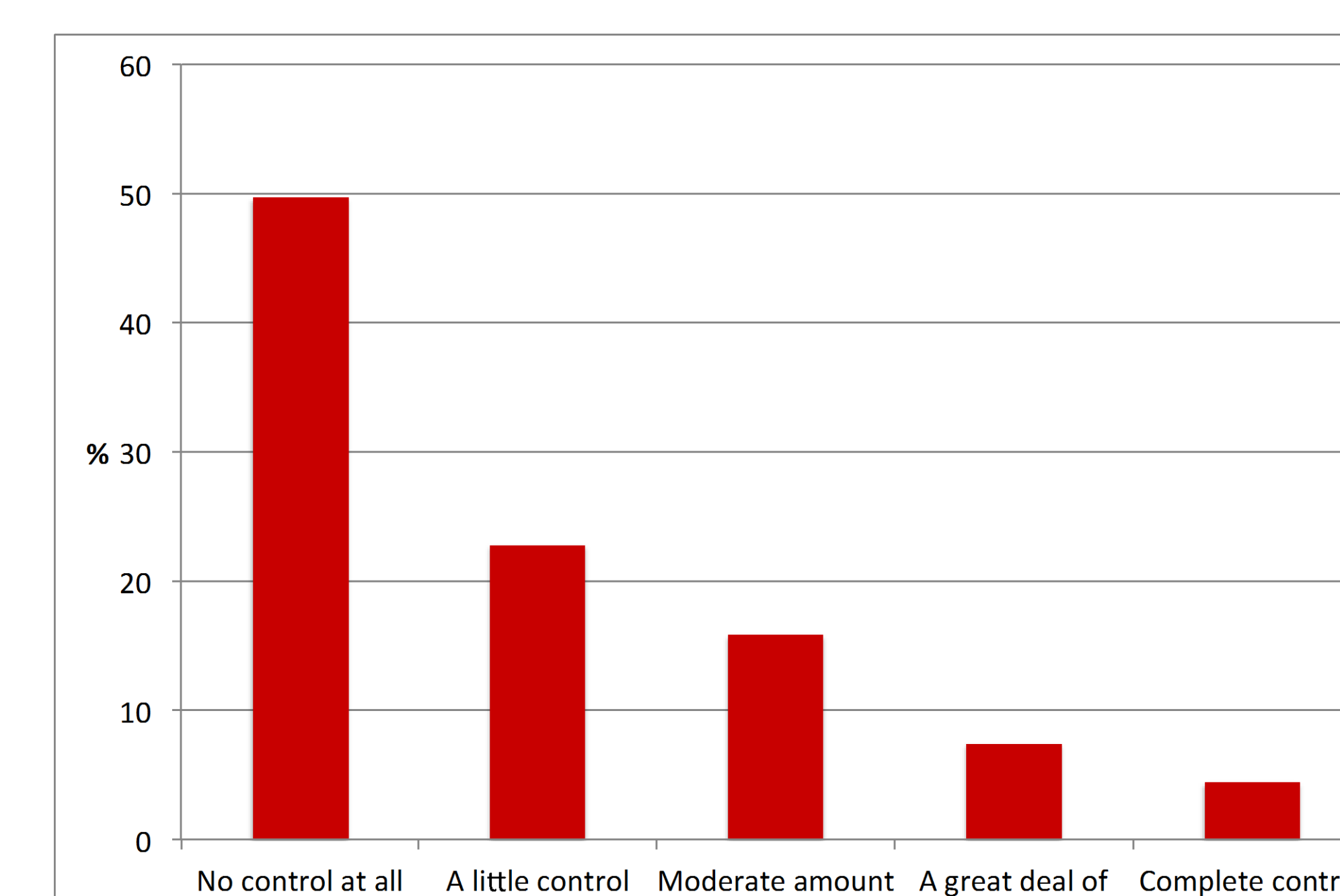


Figure 2. Perceived control over the course of MM

Table 1. PROMIS scores by level of perceived control

	At least a little control (n=137)	No control at all (n=135)	p-value*
	Mean score		
Physical function	44	41	0.009
Anxiety	50	52	0.054
Depression	48	51	0.007
Fatigue	53	56	0.011
Sleep disturbance	51	52	0.27
Satisfaction with social roles	48	44	0.001
Pain interference	49	51	0.065

* t-test

Those who reported no perceived control had significantly higher levels of anxiety, depression, and fatigue and lower levels of physical function and satisfaction with participation in social roles.

Conclusions and Future Directions

These findings demonstrate that patients with MM are experiencing differences in physical function, social roles, fatigue and sleep disturbance compared to the general population. Importantly, lacking a sense of control over the course of MM was significantly associated with poorer psychosocial outcomes, including higher levels of anxiety, depression and fatigue. Future research should examine whether enhancing support, education and lifestyle management can improve quality of life and health outcomes among patients with MM.

Acknowledgements

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