



# PRS: Myeloma & MDS

Patient Registries at Slone

## BACKGROUND

With the rapid advances in treatment for multiple myeloma and myelodysplastic syndrome (MDS), it is important to include diverse patient subgroups in clinical trials and to offer new treatments to all appropriate patients. Exploration of patients' attitudes toward participation in research, newly approved treatments, and potential treatment side effects can guide efforts to increase both participation in research and acceptance of treatments among various subgroups.

## METHODS

The Patient Registries at Slone: Myeloma & MDS are national disease-based observational registries conducted by the Slone Epidemiology Center at Boston University.

- All patients diagnosed with these diseases within 4 months of enrollment are eligible for inclusion.
- Subjects self-enroll by mail, telephone, or over the Internet.
- Subjects complete questionnaires at baseline and every 6 months thereafter. Medical records are requested with a patient release and abstracted by registry staff.
- Questionnaires obtain information on treatment, clinical events, quality of life, and attitudes toward research participation, new treatments, and possible side effects.
- The project is approved by the Boston University IRB.

In this analysis, we reviewed answers to attitudinal questions obtained from baseline questionnaires. After excluding subjects whose questionnaires were completed only by a family member, data from 139 myeloma and 150 MDS patients enrolled between June 2006 and September 2007 (with a median age of 63 years and residing in 44 states) were available for analysis. We calculated a composite "side effect concern" score based on the answers to 11 questions on specific side effects; the score had a possible range of 0-24. We tested differences in median score using the Wilcoxon Rank Sum and Kruskal-Wallis tests.

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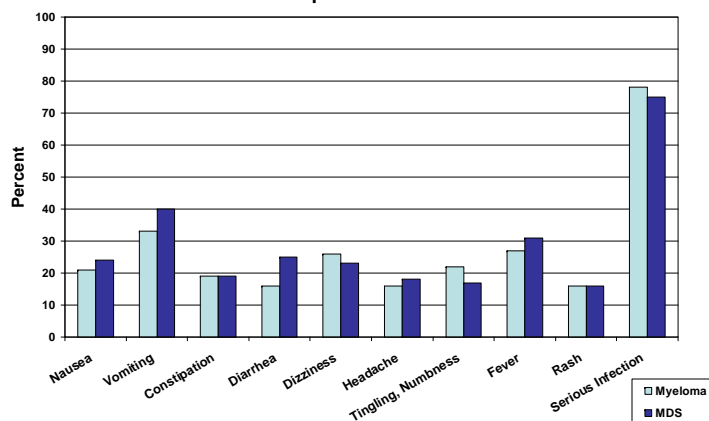
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# Attitudes Toward Participation in Research, New Treatments, and Medication Side Effects among Multiple Myeloma and Myelodysplastic Syndrome Patients – the Patient Registries at Slone: Myeloma & MDS

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## RESULTS

Proportion of Patients Who Report Being "Very Concerned" About Specific Side Effects



Willingness to Participate in Research and Try New Treatments\*

	Myeloma (n=139)		MDS (n=150)		Total (n=289)	
	No.	(%)	No.	(%)	No.	(%)
<b>Willing to participate in clinical trial</b>	111	(80)	127	(85)	238	(82)
<b>Willing to try a new treatment for which side effects not known</b>						
Very	10	(7)	14	(10)	24	(8)
Somewhat	107	(77)	113	(76)	220	(77)
Not at all	22	(16)	21	(14)	43	(15)
<b>Willing to try a new treatment that might be beneficial but could cause death</b>						
Very	21	(15)	20	(14)	41	(14)
Somewhat	87	(63)	93	(64)	180	(63)
Not at all	30	(22)	33	(23)	63	(22)

\*No material differences in concern according to age, geographic region, race, or education.

"Side Effect Concern" Score According to Various Factors

	No.	Median (range)
<b>Disease</b>		
Myeloma	135	14 (0-24)
MDS	146	14 (0-24)
<b>Willing to participate in clinical trial</b>		
Yes	233	14 (0-24)
No	40	15 (1-24)
<b>Willing to try new treatment if side effects not yet known*</b>		
Very	24	12.5 (0-22)
Not at all	43	16 (2-24)
<b>Race/ethnicity</b>		
White	253	14 (0-24)
African-American	9	17 (6-22)
Hispanic	11	14 (0-24)
Other	8	16.5 (5-22)
<b>Received treatment for myeloma</b>		
Yes	108	14 (0-24)
No	27	14 (0-24)
<b>Received treatment for MDS<sup>†</sup></b>		
Yes	91	13 (0-22)
No	55	15 (1-24)

\*p=0.01.

<sup>†</sup>p=0.02.

## COMMENT

Most myeloma and MDS patients in this national registry reported willingness to participate in clinical trials and try new treatments that had benefited some patients but for which side effects were not yet known. About 3/4 of patients reported that they would be very concerned about serious infection; there was less concern about other possible side effects. Most patients would be somewhat willing to try treatments that might help their disease but could cause death. The level of concern about side effects was similar for both myeloma and MDS patients. Higher levels of concern were associated with less willingness to try a new treatment, but were not associated with willingness to participate in research. MDS patients who had received treatment were less concerned about side effects than those who had not yet been treated.