



Classification of Myelodysplastic Syndrome in a National Registry of Recently-Diagnosed Patients – The Patient Registries at Slone: MDS

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BACKGROUND

The French-American-British (FAB) classification system for myelodysplastic syndrome (MDS) is based largely on morphology, including broad subtypes that crudely correlate with prognosis. The World Health Organization (WHO) scheme includes more extensive morphologic and cytogenetic criteria that are important not only for classification, but also for prognosis and treatment (eg: those with 5q-). Despite this, it is not currently known to what extent the WHO scheme has been adopted by practicing hematologists and pathologists.

METHODS

The Patient Registries at Slone: MDS is a national disease-based observational registry conducted by the Slone Epidemiology Center at Boston University.

- All patients diagnosed with MDS 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 to provide information on treatment, clinical events, quality of life, and attitudes toward research participation and new treatments.
- Medical records are requested at baseline and every 6 months thereafter with a patient release and are abstracted by registry staff.
- The project is approved by the Boston University Medical Campus IRB.

In this analysis, we reviewed the medical records of 174 enrollees from June 2006 through March 2008 to determine which classification scheme was used and by whom (hematologists or pathologists). We also explored possible associations between classification scheme use and demographic and treatment information obtained from patient questionnaires.

RESULTS

Table 1: Documentation of MDS Subtype and Diagnosis in 174 Medical Records

	Hematologist		Pathologist		Anywhere in Record	
	No.	%	No.	%	No.	%
No documentation of MDS*	12	7	85	49	8	5
MDS diagnosis without subtype	74	43	23	13	58	33
Subtype provided, schema unclear	33	19	13	8	32	18
WHO subtype	46	26	43	25	63	36
FAB subtype	7	4	7	4	10	6
Both WHO & FAB subtypes	2	1	3	2	3	2

*Patient reports being diagnosed.

Table 3: Treatment Status at Baseline Questionnaire According to Subtype and Diagnosis Information

Treatment	Subtype (n=108)		Diagnosis without Subtype (n=58)		No Documentation of MDS (n=8)	
	No.	%	No.	%	No.	%
Disease-modifying	27	25	14	24	2	25
Supportive only	53	49	29	50	2	25
None	28	26	15	26	4	50

Table 2: Patient Characteristics according to Subtype and Diagnosis Information

Characteristic*	Subtype (n=108)		Diagnosis without Subtype (n=58)		No Documentation of MDS (n=8)	
	No.	%	No.	%	No.	%
Age, median years	64.5		63.5		57	
Sex:						
Male	50	46	19	33	5	63
Female	58	54	39	67	3	38
Education**:						
0-12 years	23	22	11	19	1	13
Some college	34	32	21	36	4	50
College graduate	24	22	12	21	2	25
Graduate school	26	24	14	24	1	13
Race:						
White, non-Hispanic	104	98	53	91	7	88
Other	4	2	5	9	1	13

*Others examined include geographic region of residence and prescription drug coverage; no material differences were observed.

**Missing for one patient in subtype group.

COMMENT

For patients with documented MDS, WHO subtypes were recorded 40% of the time, compared to 8% for FAB subtypes; this finding from our national cohort bodes well for increasing consistency between MDS researchers and caregivers. Many fewer pathologists than hematologists documented MDS in their reports, which may be due to differential application of diagnostic criteria. No significant associations with documentation of MDS or subtype were seen for key demographic characteristics or treatment status at the time of the baseline questionnaire. However, numbers were small in some categories.