


European Registry for Low risk and Intermediate-1 risk MDS: baseline report on first 400 registered patients

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Background: The European **LeukemiaNet** has initiated a prospective, noninterventional registration study on newly diagnosed MDS patients with IPSS low and intermediate-1 risk in **eleven** participating European countries:  The **main objectives** are to describe demographics and to collect data on clinical characteristics, disease management and relevant outcomes.

Patients and Methods: The registry started accruing patients in April 2008. Until now 606 patients have been registered through a web-based reporting system. This planned report describes the demographic data of the first 400 registered patients with a median follow up of 177 days.

Results

Median age: 74 years. The majority of patients were males 250/400 except within **WHO** del(5q) which showed a female preponderance 21/27.

	N	%
Total	400	100
RA	81	20.3
RARS	84	21.0
RCMD	114	28.5
RCMD-RS	26	6.5
RAEB-1	52	13.0
MDS-U	16	4.0
5q-Syndrome	27	6.8

	Karnofsky Performance Score											Total
	10	20	30	40	50	60	70	80	90	100	Not done	
N	1	0	0	1	18	27	31	69	111	84	58	400
%	0.3	-	-	0.3	4.5	6.8	7.8	17.3	27.8	21.0	14.6	100
Median Age (Years)	77.3	-	-	74.9	80.2	80.5	76.4	74.1	71.6	70.7	74.4	73.8

Karnofsky index: related to age ($p < 0.001$) and was < 80 in 20% of the patients. The median EQ 5D score was 70 and ranged from 50 in Austria to 87 in Greece. The mean Sorrow Score of Co-morbidity was 2.4 and ranged from 1.4 in Greece to 3.0 in France. Overweight (BMI > 25) reported in 60% of the patients.

	N	Mean (SD)	Median (Range)
Serum Iron ($\mu\text{mol/L}$)	240	22.3 (10.7)	10.3 (3 to 57)
Iron Binding Capacity ($\mu\text{mol/L}$)	115	46.1 (16.3)	47 (2 to 88)
Ferritin ($\mu\text{g/L}$)	289	475 (481.0)	341 (7 to 3179)
Transferrin Saturation Level (%)	107	43.4 (22.1)	39 (7 to 97)

Median transferrin saturation level 39%, ranging from 17% in MDS-U to 53% in RARS
Median ferritin level: 341 mg/l, ranging from 121 mg/l in del(5q) to 577 mg/l in RARS

Country	Blood Transfusion (%)
Total	27.0
ND	55.6
GE	47.4
SW	44.2
SP	33.3
UK	28.1
CZ	25.8
AU	25.0
RO	21.1
FR	20.0
GR	17.0

Baseline transfusion dependency varied between registries

	MDS Treatment
Total	37%
Erythropoietin	31
G-CSF	4
Clinical Trial	3
Immunosuppressive	2
Prednisone	2
Hydroxyurea	1
Demethylating Agents	1
Other Agents	6

Most patients did not receive specific treatment at registration

Outcome & Conclusions

- Progression to leukemia or high risk MDS occurred in 13 patients
- Sixteen patients have died mainly due to non MDS-related causes (9) after a median follow-up of 175 days
- This European registry study shows that is possible to collect detailed demographic data in eleven different countries. The preliminary data show demographic differences.

Future plans

- Extend follow-up period to 5 years and the patient cohort to 2000 patients
- Include new countries (already ongoing)
- Create a prospective registry for high-risk MDS mapping onto the existing infrastructure

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