Quality of Life Burden Among Patients with Myelodysplastic Syndrome: Analysis of Survey Data

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Background & Objectives

Background
- Myelodysplastic syndromes (MDS) are a group of disorders characterized by impaired bone marrow production[1]
- More than 86% of patients with MDS are 60 years or older[2]
- Long-term survival for MDS patients is generally poor (3-year relative survival across all age groups is 45%) and inversely related to age at diagnosis[3]

Objectives
- Determine quality of life (QoL) among MDS patients as measured by the FACT-G functional assessment of cancer therapy scale
- Examine relationships between MDS patients' QoL and: hemoglobin (Hgb) levels, platelet count, age, International Prognostic Scoring System (IPSS) risk score, transfusions and prior disease-modifying therapy (DMT)

Methods

Sponsor: MDS Foundation, Inc.
Study design: Convenience sample of MDS patients were recruited to complete a one-time, web-based questionnaire
Length of study: Responses were collected from July 2013 to June 2014
Analysis:
- Descriptive statistics were conducted for the following patient characteristics:
  - Demographic information (i.e. age, gender, ethnicity, educational level, employment)
  - MDS disease risk based on IPSS score; MDS disease type
  - Transfusion history
  - Hgb levels
  - Platelet count
  - Overall mean QoL scores evaluated according to published FACT-G scoring algorithms (scale: 0 - 108)
- Regression analyses were completed to study the association between the FACT-G functional assessment of cancer therapy scale and select key factors
- Responses to each question were voluntary, therefore the total number of respondents to each item varies

Results

Demographics
- N = 727 patients
- Mean patient age was 68 years
- 47% of responders were female
- 90% of responders were Caucasian/white
- Over half of respondents had completed 4+ years of college
- 19% of responders claimed full or part-time employment at the time of survey administration
- Only 45% of patients reported knowledge of their IPSS risk score, of these:
  - 72% were lower risk (IPSS "low" and "intermediate 1")
  - 28% were higher risk (IPSS "intermediate 2" and "high")
- Over half of patients (54%) indicated specific MDS type

Patient-reported IPSS Risk Score

Legend:
- No response — 55%
- 0´ Low Risk — 14%
- 0.5-1 Intermediate Risk 1 — 18%
- 1.5-2 Intermediate Risk 2 — 8%
- >2.5 High Risk — 5%

Results (cont.)

Respondent Demographics	N (%)	Respondent Demographics	N (%)
Gender		**Highest education level completed**	
Female	234 (32.2)	4 or more years of college	277 (38.1)
Male	268 (36.9)	2 years of college	86 (11.8)
No response	225 (30.9)	High school degree or GED	117 (16.1)
Age		Less than high school	15 (2.1)
00-54	52 (7.2)	No response	232 (31.9)
55-64	85 (11.7)	**Current employment status**	
65-74	237 (32.6)	Disability	51 (7.0)
75+	128 (17.6)	Employed full-time	60 (8.3)
No response	225 (30.9)	Employed part-time	37 (5.1)
Ethnic group		Retired	316 (43.5)
African-American	5 (0.7)	Unemployed	16 (2.2)
American Indian	2 (0.3)	Other	18 (2.5)
Asian	9 (1.2)	No response	229 (31.5)
Caucasian/white	452 (62.2)		
Hispanic/Latino	16 (2.2)		
No response	224 (30.8)		

Patient-reported MDS Type[4]

Legend:
- No response — 18%
- CMML (chronic myelomonocytic leukemia) — 1%
- MDS associated with del (5q) or 5q- — 10%
- RA (refractory anemia) — 10%
- RAEB-1 (refractory anemia with excess blasts) — 4%
- RAEB-2 (refractory anemia with excess blasts) — 5%
- RARS (refractory anemia with ringed sideroblasts) — 12%
- RCMD — 6%
- Unclassified MDS — 7%
- Not sure — 27%

Transfusions
- 46% of patients reported having had at least one transfusion
- A higher percentage of IPSS higher-risk patients (73%) than lower risk patients (49%) reported having ever received transfusions
- Among the 316 respondents who required at least one blood transfusion and responded to all QoL questions, mean FACT-G score was 72.3

Respondent Transfusion History	N (%)
Reported ever receiving transfusions	
Yes	332 (45.7)
IPSS lower risk	115 (34.6)
IPSS higher risk	66 (19.9)
Risk not reported	151 (45.4)
No	223 (30.7)
Not sure	9 (1.2)
No response	163 (22.4)
Red blood cells received (N=332)	
In past 2 months	125 (37.7)
In past 1 week	74 (22.3)
Platelets received (N=332)	
In past 2 months	53 (16.0)
In past 1 week	23 (6.9)
Whole blood received (N=332)	
In past 2 months	44 (13.3)
In past 1 week	23 (6.9)

IPSS Risk Score of Patients Who Received At Least One Transfusion

Legend:
- Risk not reported — 45%
- IPSS lower risk — 35%
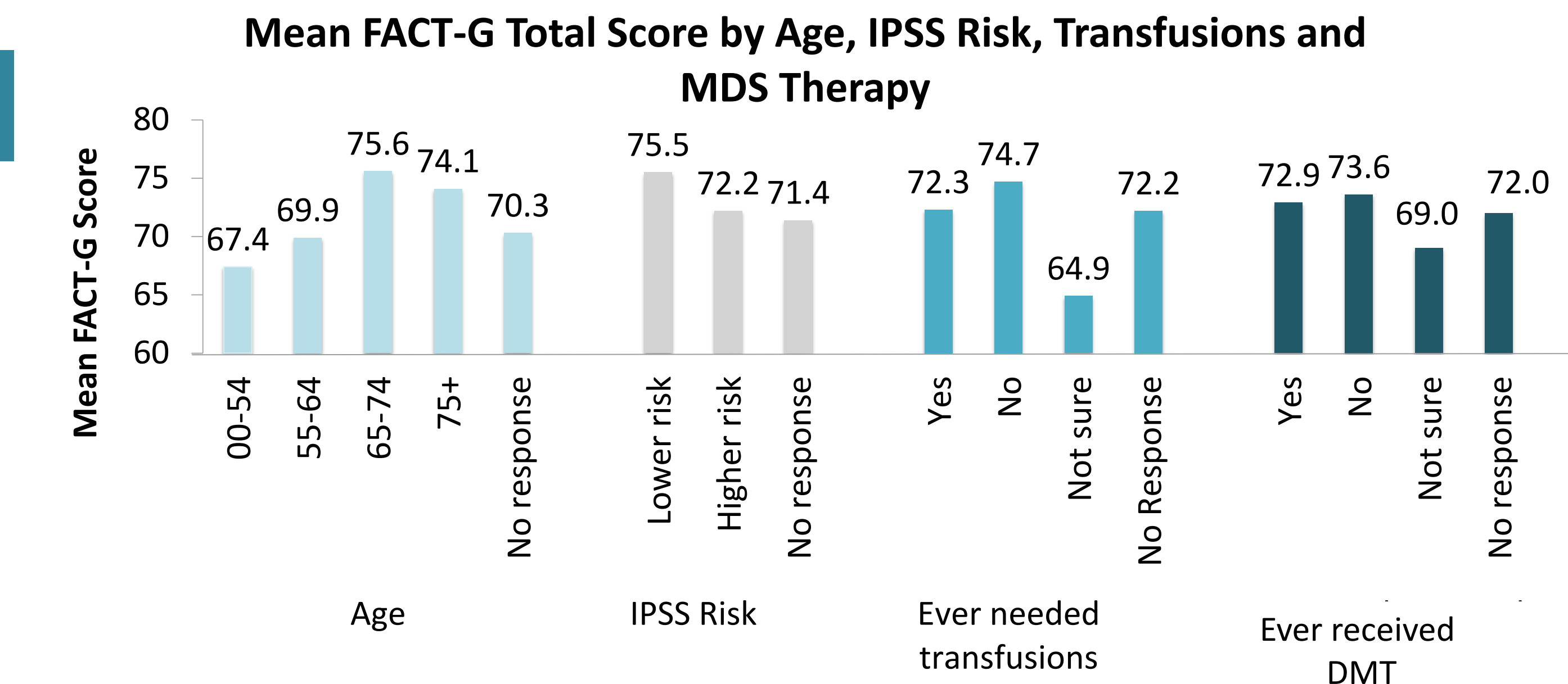- IPSS higher risk — 20%

Hgb Levels & Platelet Counts
- 57% and 53% of patients reported knowing his/her current Hgb levels and platelet count, respectively
- Nearly three fourths of patients knew the date of their most recent platelet count (70%) or hemoglobin evaluation (74%):
  - Platelet count:
    - 494 (68%) patients stated that counts were conducted up to 3 months before completing the survey
    - 18 (3%) patients' platelet counts were completed over 3 months prior to submitting a survey response
  - Hgb level:
    - 518 (71%) patients reported Hgb evaluations within three months prior to completing the survey
    - Just 21 (3%) patients' Hgb levels were assessed more than 3 months before the survey

Patient knew his/her current:		
	Hemoglobin level, N (%)	Platelet count, N (%)
Yes	417 (57.4)	382 (52.5)
IPSS lower risk	180 (43.2)	171 (44.8)
IPSS higher risk	64 (15.3)	64 (16.8)
Risk not reported	173 (41.5)	147 (38.5)
No	68 (9.4)	101 (13.9)
Not sure	49 (6.7)	59 (8.1)
No response	193 (26.5)	185 (25.4)

QoL
- Among patients who responded to all FACT-G items (N=543), mean FACT-G score was 73.1
- Mean FACT-G scores varied the greatest by:
  - Patient age (67.4-75.6, p-value = 0.004)
  - Hgb levels (63.5-77.8, p-value < 0.001)
  - Platelet count (69.5-76.9, p-value = 0.014)
- In regression analyses, older age, higher Hgb levels and having fewer comorbidities were significantly associated with higher FACT-G total scores

Mean FACT-G Total Score by Hgb Level (p-value < 0.001)

Mean FACT-G Total Score by Platelet Count (p-value = 0.014)

Mean FACT-G Total Score by Age, IPSS Risk, Transfusions and MDS Therapy

DMT
- Mean FACT-G for patients receiving DMT was 72.9
- 286 (39.4%) respondents reported previously receiving DMT, of whom:
  - 88 (30.8%) were IPSS lower risk (low risk and intermediate risk 1)
  - 67 (23.4%) were IPSS higher risk (intermediate risk 2 and high risk)
  - 131 (45.8%) did not report a risk score
  - 179 (62.6%) were still receiving DMT at the time of the survey
  - 12 (4.2%) reported participating in a clinical trial

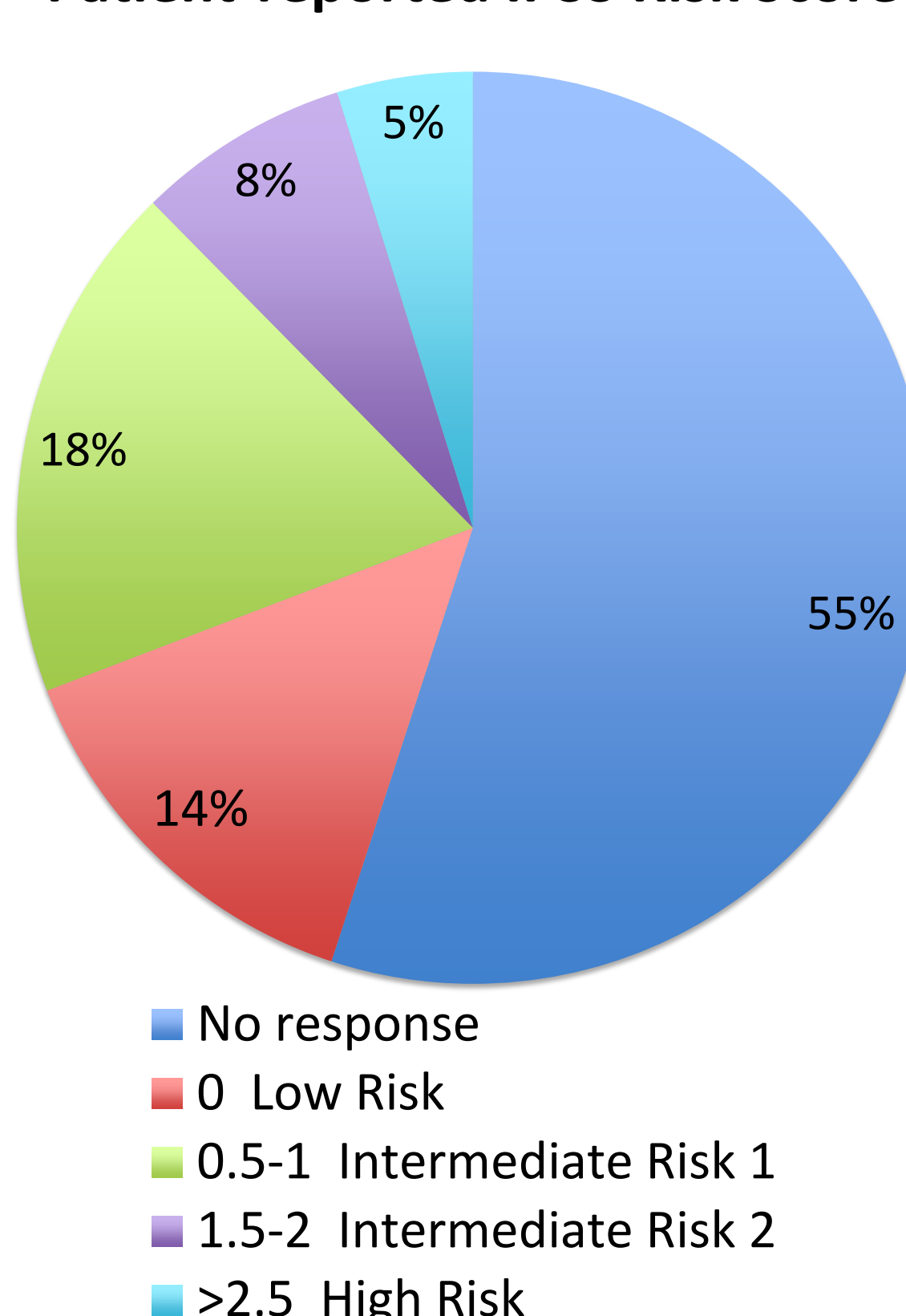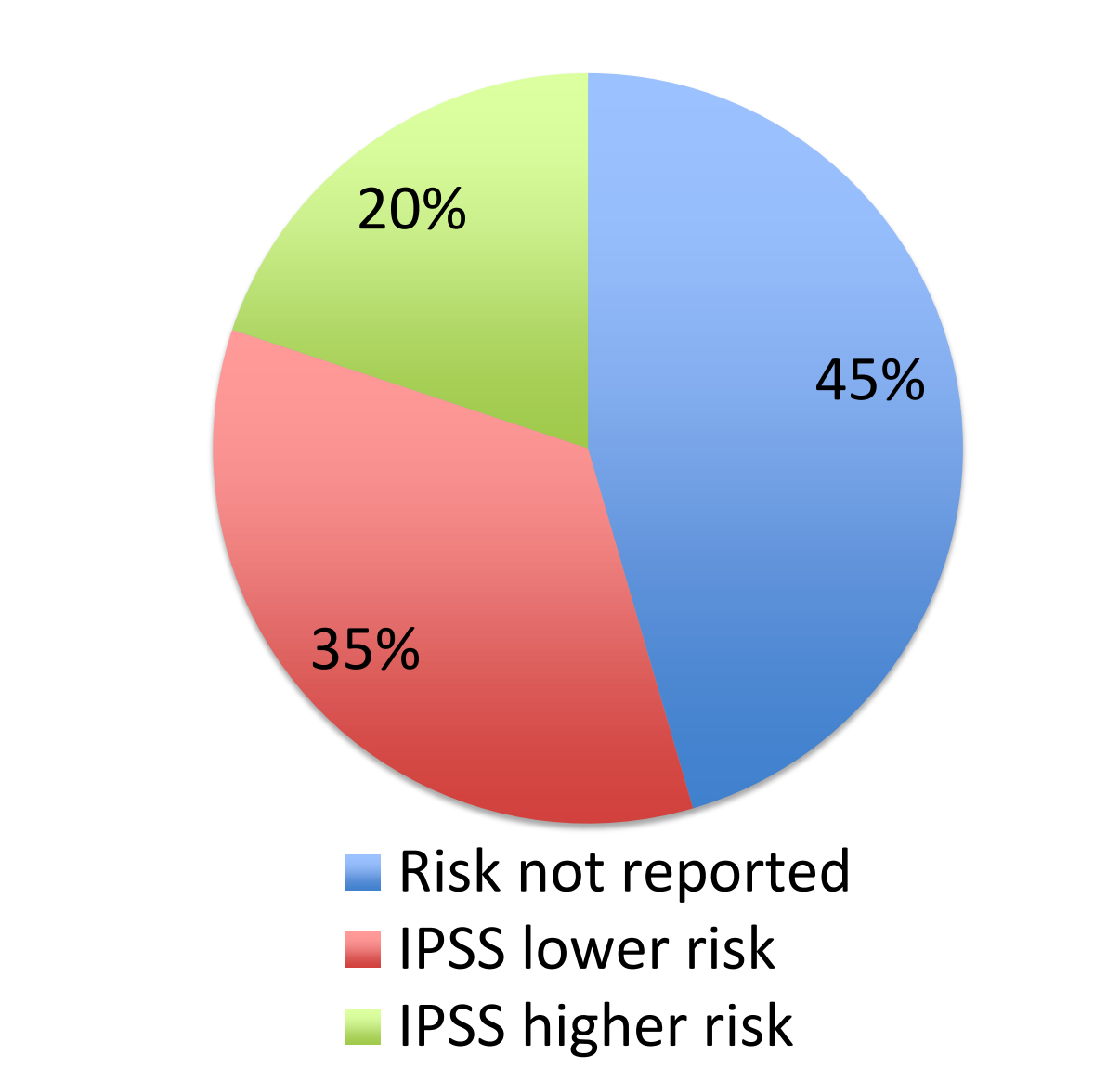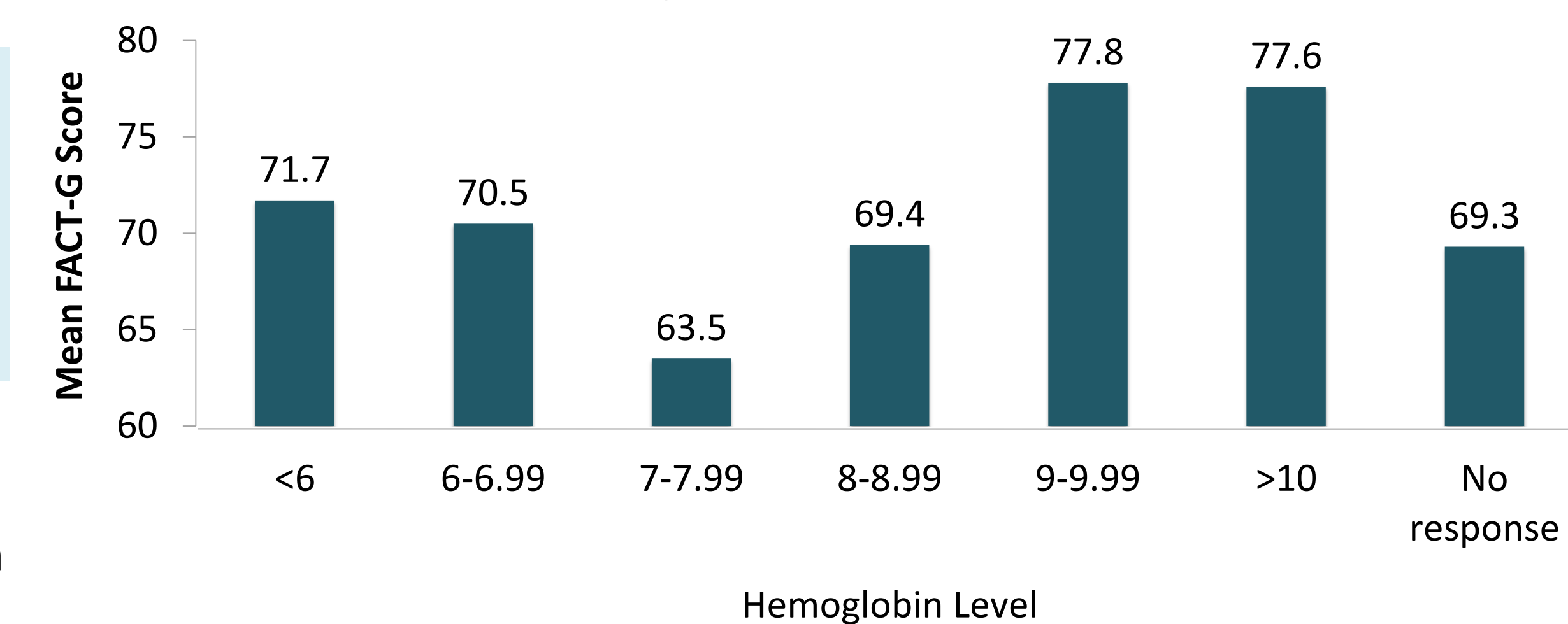**Comparison with Previously-surveyed MDS Patients[5]**
- In 2009, MDS Foundation, Inc. disseminated a survey to patients with MDS that included a standardized questionnaire designed to assess QoL (N = 199)
- Responses were evaluated according to published FACT-G scoring algorithms
- Compared with respondents of the 2009 survey, a greater proportion of current study respondents were:
  - Older (mean age: 68 vs. 63 years)
  - More likely to:
    - Be female (47% vs. 43%)
    - State Caucasian/white ethnicity (90% vs. 85%)
    - Have completed 4+ years of college (56% vs. 51%)
    - Report high IPSS risk (28% vs. 21%)
  - Less likely to:
    - Currently work full or part-time (19% vs. 33%)
    - Claim knowledge of their IPSS risk score (45% vs. 53%)

Conclusions

- The MDS patient population has changed somewhat (i.e., ethnicity, education, work status, and IPSS risk), but not dramatically, since 2009.
- Mean FACT-G scores varied most dramatically when evaluating patient QoL by Hgb levels, platelet counts and patient age; thus these parameters significantly impact MDS patients' QoL.
- Until therapy options that minimize symptomatic cytopenias become available, more research is needed to identify better ways to improve the overall well being of symptomatic MDS patients.
- Focusing the attention of physicians, family members, and other MDS support structures on improving aspects of patient care will benefit patients and their caregivers alike.

References

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