

Disparities in Perceptions of MDS Understanding Between Patients and Nurses: AA&MDSIF 2014 Survey Results

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AA&MDSIF Survey Goals

- Compare physician, nurse and patient responses to identify misperceptions and disparity
- Explore the impact of ageism and comorbidities on access to treatments, including supportive care
- Explore reasons for treatment discontinuation for specific treatments
- Expand the inquiry into patient education and services to include format, timing and benefit
- Examine the impact that the AA&MDSIF Treating MDS Toolkit has on patient education
- Gather additional information on factors that impact treatment adherence



Methodology

- Surveys:
 - Developed and field tested with patient, physician and nursing panels
 - Adjustments made based on feedback and from the AA&MDSIF
 - Approved by medical advisors
 - Submitted and approved by the IRB
 - Consent included in the email with link to survey

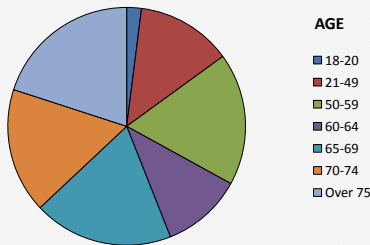


Methodology

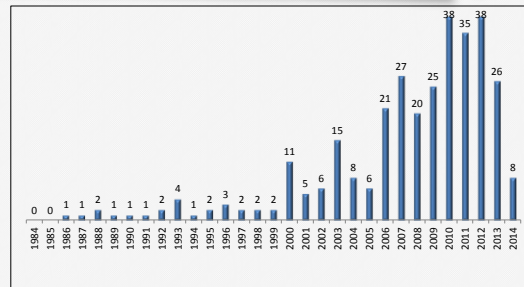
- Links to online surveys sent to patients, physicians and nurses within the AA&MDSIF database:
- Patient Survey:
 - Emailed to 4,129 patients
 - Patient analysis based on 314 complete responses
- Physician and Nurse Survey:
 - Emailed to 4,594 healthcare providers
 - Physician analysis based on 51 complete responses
 - Nurse analysis based on 165 complete responses



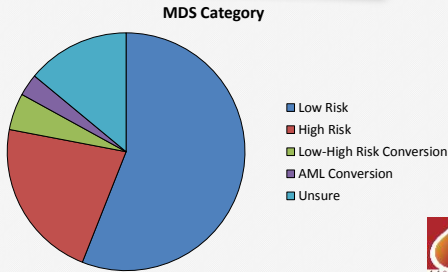
MDS Patient Demographics



MDS Patient Diagnosis



MDS Patient Classification



MDS Patient Co-Morbidities

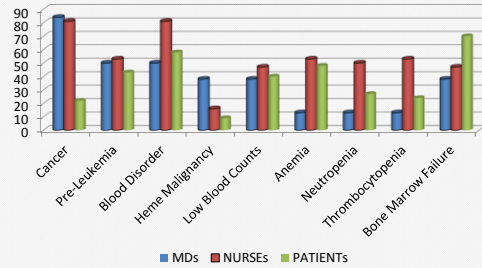
CONDITION	PERCENTAGE
No other medical problems	22%
Heart disease or heart surgery or hypertension	37%
Kidney disease	9%
Lung disease (asthma, emphysema, etc.)	14%
Liver abnormalities	9%
Stroke or problems with blood vessels	6%
Blood clots	7%
Autoimmune disorders (Lupus, rheumatoid arthritis, psoriasis)	12%
Endocrine disorders (diabetes, thyroid disease)	27%
Other cancers	16%
Mental health problem (depression, anxiety, etc.)	23%
Other blood disorders	5%
Other	17%

Myelodysplastic Syndromes

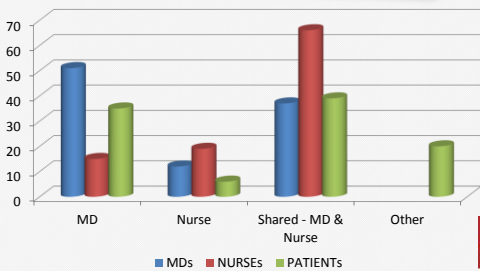
Myelodysplastic Syndromes (MDS) are a complex, diverse and incurable collection of myeloid malignancies characterized by progressive bone marrow failure, cytopenias and increased risk of acute myeloid leukemia (AML) transformation



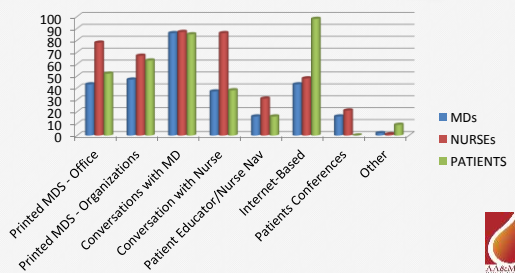
MDS Description



MDS Educational Providers



MDS Educational Format

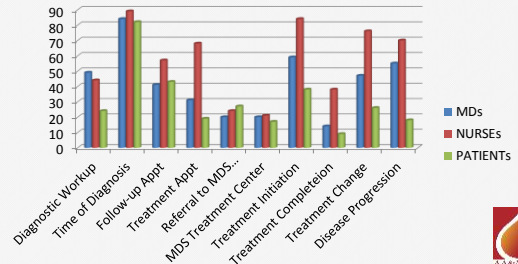


MDS Web-Based Sites

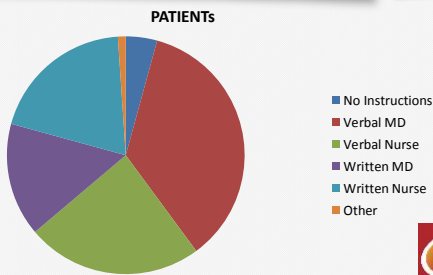
- Aplastic Anemia & MDS International Foundation (www.AAMDS.org)
- Be the Match (www.marlow.org)
- Clinical Trials (www.clinicaltrials.gov)
- Leukemia and Lymphoma Society (www.lls.org)
- MDS Beacon (www.mdsbeacon.com)
- MDS Foundation (www.mds-foundation.org)
- National Institutes of Health (www.nlm.nih.gov)
- National Cancer Institute (www.cancer.gov)
- National Comprehensive Cancer Network (www.nccn.com)
- Web MD (www.webmd.com)



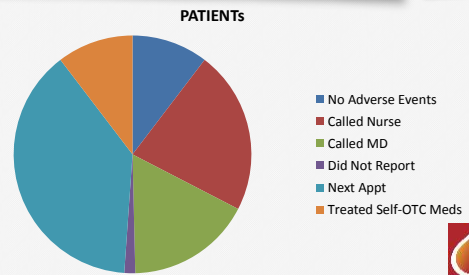
MDS Educational Timing



MDS Adverse Event Education



MDS Adverse Event Reporting



Survey Conclusions

- Patients:
 - Limited ongoing access to services after initial diagnosis
- Physician and Nurses:
 - Ageism continues to manifest in lack of willingness or commitment to a course of treatment for much older patients
 - Lack of understanding persists on how to effectively treat MDS in the context of comorbidities
 - Disconnect regarding the impact of treatment on quality of life



Survey Conclusions

- Physicians and Nurses:
 - Disconnect in communication:
 - Reasons for treatment discontinuation:
 - Disease progression vs treatment ineffective
 - Experiences/reporting of side effects
 - Lack of MDS education continues to be an issue for community health care providers
 - Lack of ongoing and repetitive education about the MDS disease, treatment and adverse events, particularly in disease progression



Additional Survey Results Presented at ONS Congress

- Use of the AA&MDSIF “Treating MDS Toolkit” by Oncology Nurses Can Enhance MDS Disease State and Treatment Related Adverse Event Education (Poster Presentation)
- Available from the Aplastic Anemia & MDS International Foundation (AA&MDSIF) at www.AAMDS.org

