Patient and Family Resources for Living With Myelodysplastic Syndromes

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Primarily a disease affecting older adults, myelodysplastic syndromes (MDS) are a class of incurable myeloid malignancies with variable clinical presentation, treatment recommendations, and prognoses. Although effective communication between healthcare professionals and patients and their caregivers is a significant part of optimizing clinical outcomes, studies have shown that all three frequently have an incomplete understanding of MDS, its therapeutic options, and the fact that MDS is a malignancy. In addition, the advanced age of the patient population, high frequency of comorbidities, and variability of disease outcomes based on risk status require consistent communication across a wide number and type of healthcare providers as well as an individualized approach to patient and caregiver education. This article discusses these challenges and provides a number of resources designed to help educate healthcare professionals, patients, and caregivers.

M yelodysplastic syndromes (MDS) represent a heterogeneous group of myeloid malignancies with a peak incidence in the seventh and eighth decades of life. The disease is characterized by ineffective hematopoiesis with variability in clinical presentation, treatments, disease trajectory, and prognosis (Kurtin & Demakos, 2010). Although scientific discoveries have been robust, MDS remains largely an incurable disease. A number of studies have indicated that the leading cause of death in patients with MDS is related to the disease itself in more than 75% of patients (Dayyani et al., 2010). However, with the majority of patients being considered “elderly,” healthcare providers (HCPs), patients, and their caregivers often hesitate to pursue disease-modifying therapies based on chronological age alone, despite evidence showing positive effects on overall survival and quality of life (Kurtin, 2010; Life Beyond Limits, 2011). Additional factors noted to limit treatment options offered to the older adult population include fear of toxicity, limited expectation of benefit, or ageism (Carreca & Balducci, 2009; Kurtin, 2010). Patients are reluctant to pursue active treatment for similar reasons, as well as concern for the cost of treatment and the strain on caregivers (Kurtin, 2010).

In addition to confirming the low threshold for tolerating moderate adverse events in a predominantly older adult population, several surveys of patients and providers have underscored the ambiguity in describing MDS as a myeloid malignancy and a reluctance to offer disease-modifying treatments based on risk analysis (Kurtin & Demakos, 2010; Sekeres, 2011; Sekeres et al., 2011). As a result, patients often are unable to describe the characteristics of their disease, including their International Prognostic Scoring System risk category, blasts percentage, cytogenetic abnormalities, and how these attributes correlate with their treatment options and prognosis (Demakos & Kurtin, 2011; Sekeres et al., 2011). A minority of patients in these surveys had been told that MDS is a malignant disorder. Many oncology practitioners today may see fewer than 10 patients with MDS per
MDS-Specific Organizations

- Life Beyond Limits
  www.mds/lifebeyonlimits.org
  Brings together an independent group of MDS experts to raise awareness of ageism in access to care for patients with MDS
- MDS Beacon
  www.mdsbeacon.com
  Objective and unbiased news and other information related to MDS; mission is to be a key Internet resource and online community for patients with MDS, their families, and others interested in MDS
- MDS Foundation
  www.mds-foundation.org
  Multidisciplinary, international, nonprofit organization dedicated to the education of professionals, patients, and caregivers; facilitation and support of clinical trials; and development and support of patient advocacy groups
- United Kingdom MDS Patient Support Group
  www.mdspatientsupport.org.uk
  Offers support, information, referral advice, and patient information in the United Kingdom

Organizations That Include MDS Within the Scope of Hematologic Malignancies

- Aplastic Anemia and MDS Foundation
  www.aamds.org
  Nonprofit health organization dedicated to supporting patients and families living with aplastic anemia, MDS, paroxysmal nocturnal hemoglobinuria, and related bone marrow failure disease
- Leukaemia and Lymphoma Research Foundation
  www.leukaemialymphomaresearch.org
  Programs for support of all of the different blood cancers for patients and their families
- Leukaemia Care
  www.leukaemiacare.org.uk
  Resources for people affected by Hodgkin, non-Hodgkin, and other lymphomas; myeloma; MDS; aplastic anemia; and myeloproliferative disorders
- Leukemia and Lymphoma Society
  www.lls.org
  Mission is to cure leukemia, lymphoma, Hodgkin disease, and myeloma and improve the quality of life of patients and their families

General Resources

- American Cancer Society
  www.cancer.org
- American Society of Clinical Oncology
  www.asco.org and www.cancer.net
- American Society of Hematology
  www.hematology.org
- CancerCare
  www.cancercare.org
- Medline Plus®
- Merck Manual Home Edition for Patients and Caregivers
  www.merckmanuals.com/home/index.html
- National Anemia Action Council
  www.anemia.org
- National Heart, Lung and Blood Institute
  www.nhlbi.nih.gov
- National Marrow Donor Registry
  www.marrow.org

Financial Assistance Programs

- American Cancer Society
  www.cancer.org
- Anthony Nolan Trust
  www.anthonynolan.org
  Dedicated to bone marrow transplantation and running a database of donors
- CancerCare Co-Payment Assistance Foundation
  www.cancercarecopay.org
- Cancer Financial Assistance Coalition
  www.cancerfac.org
- Chronic Disease Fund
  www.cdfund.org
- HealthWell Foundation
  www.healthwellfoundation.org
- Lance Armstrong Foundation
  www.livestrong.org
- Leukemia and Lymphoma Society
  www.lls.org/copay
- MacMillan Cancer Support
  www.macmillan.org.uk/Home.aspx
  General information, assistance, and financial advice
- Patient Advocate Foundation Program Co-Pay Relief Program
  www.copays.org
  www.mds-foundation.org/for-patients-visitors

Clinical Trials and International Drug Approval Information

- European Medicines Agency
  www.ema.europa.eu
  Decentralized agency of the European Union, located in London; responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union
- Health Canada
  www.hc-sc.gc.ca
  Provides a notice of compliance (NOC) for full approval of a new drug or an NOC with conditions in Canada
- National Cancer Institute, National Institutes of Health
  www.clinicaltrials.gov
  Registry and results database of federally and privately supported clinical trials conducted in the United States and around the world
- National Institute of Health and Clinical Excellence
  www.nice.org.uk
  Guidance for cost effectiveness of treatments for England and Wales
- Nordic MDS Group
  www.nmds.org
  Provides Nordic guidelines for MDS management online and patient information in all Nordic languages
- Pharmaceuticals and Medical Devices Agency
  www.pmda.go.jp
  Regulation of drug availability in Japan
- Therapeutic Goods Administration
  www.tga.gov.au
  Division of the Australian government’s Department of Health and Aging; responsible for regulating therapeutic goods including medicines, medical devices, blood, and blood products
- U.S. Food and Drug Administration
  www.fda.gov
  Approval required for commercial availability of therapy in the United States

FIGURE 1. Patient and Caregiver Resource Catalog for Myelodysplastic Syndromes (MDS)
Patients or caregivers may contact the patient liaison directly by calling (toll-free) 800-637-0839 or via e-mail to ahasan@mds-foundation.org.

The MDS Foundation offers a patient advocacy and outreach program. Patients or caregivers may contact the patient liaison directly by calling (toll-free) 800-637-0839 or via e-mail to ahasan@mds-foundation.org.

Multiple languages

Patient Resources on Myelodysplastic Syndromes

Several surveys of both patients and HCPs have provided some insight into the characteristics of patients with MDS, what patients with MDS understand about their disease, what they perceive as unmet needs, and what they feel are the optimal characteristics of HCPs. The epidemiologic characteristics of the disease in all surveys confirmed the prevalence of MDS in patients older than age 65 years (Demakos & Kurtin, 2011; Ma, Does, Raza, & Mayne, 2007; Sekeres, 2011). That fact is important when considering the best approach to patient education and support given the trend toward online resources.

The MDS Foundation provides a patient advocacy and outreach program, which includes a full-time patient liaison available via telephone and e-mail. Patient phone calls to the MDS Foundation, together with patient surveys conducted as a part of patient and caregiver support programs supported by the MDS Foundation and the United Kingdom MDS Patient Support Group, have provided insight into the educational and supportive care needs of patients with MDS. Members of the International Nursing Leadership Board for the MDS Foundation serve as facilitators for the sessions. The most commonly asked questions in the sessions have been used as a template for the development of patient and caregiver education and support materials (see Appendix A).

Expectations of Patients and Providers

Working with patients facing an incurable disease requires time, compassion, clarity of message, and resilience on the part of HCPs. The shift toward survivorship care planning and personalized medicine places additional responsibilities on the oncology HCP to maintain a current working knowledge of a variety of conditions and treatment standards (Litton et al., 2010). Given the age of most patients with MDS, comorbid conditions are common, often requiring involvement of a number of specialists in addition to a primary care physician (Kurtin & Demakos, 2010). With the limited number of patients with MDS seen in a general oncology practice, the older age of most patients with MDS, and the provision of the majority of care in the outpatient setting where contact with the provider may be limited to 15–20 minutes per visit, clarity and consistency of information provided to patients and caregivers across all HCPs is an imperative and, yet, a daunting task. In addition, patients with cancer identify knowledgeable HCPs and adequate time for questions as desirable attributes of HCPs, emphasizing the need to employ a variety of educational strategies across disciplines.

Most patients facing a cancer diagnosis want to understand their disease, prognosis, available treatment options, potential adverse events, and expected duration of therapy (Protiere,
Implications for Practice

- Myelodysplastic syndromes are a class of incurable diseases requiring compassionate, clear, and consistent communication among healthcare providers (HCPs), patients, and caregivers.
- The majority of patients and caregivers want to understand their disease, prognosis, available treatment options, expected duration of therapy, potential adverse events, and strategies for taking an active role in their care.
- Effective patient, caregiver, and HCP communication will promote patient and caregiver participation in the decision-making process and self-care.

Preparation for the Patient and Family

Development of a consistent evidence-based description of MDS as a myeloid malignancy, defining risk-adapted treatment options including supportive care, and identification of available resources and programs for patient and caregiver support are critical to ensuring optimal outcomes. Adapting strategies to incorporate international variances in treatment approaches based on available therapies and resources is necessary. Individualizing support for each patient based on available resources including social support, availability of caregivers, financial resources, lifestyle, and personal choices for care and learning styles will promote the best outcome. Incorporating a multidisciplinary team approach including HCPs, social services, financial assistance counselors, support groups, and patient navigators is recommended.

Local, regional, national, and international programs and organizations focused on MDS, hematologic malignancies, and general cancer resources (including financial assistance programs) provide important patient and caregiver resources (see Figure 1). Publications specific to the patient with MDS provide additional patient and caregiver support for those patients without access to or not comfortable with online resources (see Figure 2). As with many diseases in older adult populations, reliance on family members or friends to maintain the prescribed treatments, including travel to appointments, may place additional stressors on the patient and their support network. Careful evaluation of functional status, ability to tolerate treatments, effect of disease progression, and general overall health and family dynamics can provide the best opportunity for support of these patients. Assessment of activities of daily living may allow detection of deficiencies or deficits that require early intervention before they become problematic (Kurtin & Demakos, 2010).

Effective patient-caregiver-HCP communication will result in optimal outcomes. Communication promotes patient and caregiver participation in the decision-making process and self-care.

TABLE 1. Active Clinical Trials in MDS

<table>
<thead>
<tr>
<th>Agent</th>
<th>Mechanism of Action</th>
<th>Phase</th>
<th>Indication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arry-614</td>
<td>P38MAPK inhibitor</td>
<td>II</td>
<td>Lower risk</td>
</tr>
<tr>
<td>Gimatecan</td>
<td>Topoisomerase inhibitor</td>
<td>I</td>
<td>Lower and higher risk that have failed prior treatment</td>
</tr>
<tr>
<td>Alemtuzumab</td>
<td>Anti-CD52 immune modulation</td>
<td>II</td>
<td>Lower risk, hypoplastic</td>
</tr>
<tr>
<td>Oral azacitidine</td>
<td>Hypomethylating agent</td>
<td>II</td>
<td>Lower risk</td>
</tr>
<tr>
<td>Clofarabine</td>
<td>Nucleoside analog</td>
<td>II</td>
<td>Intermediate and higher risk</td>
</tr>
<tr>
<td>Vatalanib</td>
<td>Oral VEGF tyrosine kinase inhibitor</td>
<td>II</td>
<td>Primary or secondary MDS, any FAB subtype</td>
</tr>
<tr>
<td>Sapacitabine</td>
<td>Nucleoside analog</td>
<td>III</td>
<td>Intermediate and higher risk</td>
</tr>
<tr>
<td>Lenalidomide</td>
<td>IMiD® immunomodulatory agent</td>
<td>III</td>
<td>Lower risk, non-del(5q)</td>
</tr>
<tr>
<td>ON190</td>
<td>Unknown</td>
<td>III</td>
<td>Hypomethylating failure</td>
</tr>
</tbody>
</table>

FAB—French-American-British; MAPK—mitogen-activated protein kinase; MDS—myelodysplastic syndromes; VEGF—vascular endothelial growth factor

Note: Based on information from ClinicalTrials.gov, 2012.
and caregivers by providing clear, consistent, individualized information about their MDS, treatment plan, prognosis, and strategies for support is critical to effective management of patients. Despite the incurable nature of MDS, patients may live many months or years with this disease and will benefit from the numerous available resources. A compassionate, well-informed, and realistically optimistic oncology professional can make a world of difference to patients with MDS and their caregivers.

References


For Exploration on the Go

Access information about patient resources and support organizations in the United States and internationally from Life Beyond Limits by opening a barcode scanner on your smartphone. Point your phone at the code and take a photo. Your phone will link to the content automatically. Retrieve this content at www.mdslifebeyondlimits.org/about-mds/resources.
APPENDIX A. Most Frequently Asked Questions by Patients With Myelodysplastic Syndromes (MDS) and Their Caregivers

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What new treatments are on the horizon to treat patients with MDS? (Garcia-Manero, 2011, Kurtin, 2011)

- Clinical trials continue to explore treatment options for MDS and are always recommended for diseases that have limited treatment options, such as MDS. These trials offer hope to patients who have had limited benefit from approved therapies or have high-risk disease thought to have limited potential for benefit from these therapies. Each country has approved mechanisms for clinical trial oversight and drug approval.

Are blood transfusions dangerous? (Kurtin, 2011; National Comprehensive Cancer Network, 2011)

- The normal body mechanism for control of iron stores is highly efficient. Each unit of transfused blood delivers iron in excess of the normal daily requirements. After repeated transfusions, excess iron storage exceeds the levels that can be controlled by normal iron homeostatic mechanisms, leading to the formation of toxic iron storage and subsequent cellular damage.
- A strong correlation exists between transfusion intensity (number of units received over time) and organ damage.
- Iron accumulation results in end-organ damage.
  - Heart: congestive heart failure
  - Liver: elevated liver function tests, hepatomegaly, pain
  - Endocrine glands: diabetes
  - Bone marrow: dysfunctional hematopoiesis
- Based on these data, transfusion dependence is considered an indication to initiate disease-modifying treatment for MDS.

How do I select a bone marrow transplantation center? (National Marrow Donor Program, 2011)

- There are many factors to consider when choosing a transplantation center. Some patients look at a center’s experience with certain diseases or ages of patients. Other patients choose a center close to their family and friends. Some things you and your referring doctor can find out about transplantation centers are the following.
  - What experience does this transplantation center have?
  - What do transplantation center survival statistics mean?
  - How does the number of transplantations conducted for your disease at this center compare with other centers?
  - What are the patient- and donor-matching levels required at this center?
  - What are some of the pretransplantation costs at this center?
  - Is this center covered under your insurance plan?

What can I do to keep myself healthy?

- The general principles of a healthy lifestyle remain important. A balanced diet, daily activity and exercise as tolerated, and participation in activities of enjoyment are important to maintain optimal health and well-being. Ongoing management of other health conditions is important to optimal health and continued eligibility for future treatment options.

APPENDIX A. Most Frequently Asked Questions by Patients With Myelodysplastic Syndromes (MDS) and Their Caregivers Participating in the MDS Foundation Patient Advocacy Programs or Quality-of-Life Sessions (Continued)

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