What is the impact of being diagnosed with myelodysplastic syndromes (MDS)? What are the physical/psychosocial ramifications of RBC transfusions to manage the extreme fatigue and weakness that accompany refractory anemia; of parenteral or oral iron chelation therapy for iron overload after multiple RBC transfusions; or of receiving erythropoietin or platelet transfusions to control spontaneous or frequent bleeding because of thrombocytopenia? What is the QoL impact of treatment with any one of the three MDS drugs approved by the US Food and Drug Administration (FDA)?

It is important for clinicians to know how MDS affects patients physically, mentally, spiritually, emotionally, and socially. In a perfect world, clinicians would intuitively understand how patients’ quality of life (QoL) changes with a diagnosis of MDS. They would know how to elicit relevant information from their patients that would shed light on the full patient experience of MDS and its management. They would use QoL information to refer individual patients for specific needs, such as physical or occupational therapy or psychological counseling. Treatment would extend to the “MDS family”—patients and their caregivers.

We are beginning to collect relatively comprehensive qualitative QoL data that can teach us about the impact of MDS on patients at all levels. This information can help us to be more knowledgeable about all aspects of this widely heterogeneous bone marrow failure disorder, and will enhance our skills in communicating the basic pathobiology of MDS and the clinical consequences of both the disease and its treatments.

A broadened knowledge of MDS that includes QoL issues will enable us to direct patients toward appropriate patient education materials and additional resources such as patient support and advocacy groups.

MDS PATIENT FORUMS PROBE QOL ISSUES

Beginning in 2004, the MDS Foundation Inc. (www.mds-foundation.org), an international nonprofit organization established by physicians and researchers to foster the development and exchange of new information about the disease, convened forums for patients and their families (spouses, children) or caregivers to discuss QoL issues. A total of 29 MDS patient forums have been held in the US and in Europe (in cities with academic medical centers that have clinical research programs in MDS) through June 2007.[1–3]

Clinical nurse specialists with expertise in QoL issues among MDS patients conducted the forums, which included open dialogue and question-and-answer sessions. Anonymous questionnaires were used to assess patients’ knowledge about their disease, feelings about their relationships with their physicians, perceptions of attitude and support offered by health care providers, and the effect of the various management or treatment strategies on QoL.

THE BURDEN OF MDS

Not surprisingly, the burden of MDS—the disease and its management—has wide-ranging effects on patients’ lives (see Table 1), and telling statements have been shared by patients attending the patient forums. (See box, “MDS Patients Speak Out”). It is precisely this kind of qualitative information that can help clinicians to better understand patients’ feelings of fear, anxiety, anger, frustration, loneliness, depression, and helplessness. Fear of the future (the unknown) is especially powerful in younger adult patients.

One participant at a patient forum, for example, said she is haunted by the question, “Will I ever have children?” Her question also teaches us that more young patients are facing the possibility of dying, on top of the hard reality that they will have difficulty living their lives as they had planned. Although about one-third (35%) of MDS patients attending the MDS Foundation Patient Forums indicated that they carry out their normal lives with only minor symptoms and none indicated that...
they required specialized care or hospitalization (see Figure 1), questionnaire responses indicated that fatigue frequently and significantly affects QoL, impacting patients’ participation in social and family life and their ability to perform activities of daily living—25% reported it “takes an effort to engage in normal activities”; 16% reported they cannot perform active work; and an additional 9% reported they require “occasional” or “considerable” assistance.

Patients expressed their frustration with what they called their declining health, in statements such as, “I’m just too tired,” “I can’t play with my children (grandchildren),” and “I can’t even walk up the stairs without stopping to get my breath.”

The vast majority of patient forum participants who spoke said that they were looking forward to the remainder of their lives (retirement, travel, raising their children or grandchildren), but that their worlds changed forever when they were diagnosed with MDS.

These patients went on to say that the disease forced them to give up the things that make their lives worth living and they now are simply too tired to participate in those activities. Consistent with these findings, results from an Internet-based survey in 359 patients with MDS showed that excessive fatigue was the most common symptom, reported in 89% of the surveys. Fatigue was also found to be associated with significant impairment of health-related QoL and the ability to work or to participate in desired activities.[4]

Patients’ responses to the questionnaires reflected substantial feelings of life disruption due to MDS and the time required for disease management. For example, one patient forum participant reported, “I spend 8 hours every week getting my blood transfusions... but they make me feel so much better for a few days...It’s 8 hours out of my life, but it really helps me to live.”

Actually, more than 8 hours is spent by patients and caregivers on this process, when blood tests, blood typing, and crossmatching are considered.

Physician or clinic visits, diagnostic testing (including frequent blood tests), blood transfusions, treatment, travel time, and symptom and adverse event management contribute to patients’ feelings of “loss of life control.”

PATIENT KNOWLEDGE
What do MDS patients know about their disease and their prognosis? Every newly diagnosed MDS patient, regardless of whether he or she articulates it, has a reaction epitomized by the comment: “I have been diagnosed with MDS, but I don’t know what it is.” Family members often feel this way also. Other patients were told they have cancer, leading family members or caregivers to ask, “He’s going to die, isn’t he?”

MDS patients learn a tremendous amount about their disease in a relatively short time. Their responses to queries about their knowledge of MDS revealed that they are extremely interested in educating themselves and actively search out answers about MDS and its treatments, including “cures.” Responses to the questionnaires as well as the open dialogue sessions at the patient forums showed that MDS patients know their own MDS history very well.

More than half of responding patients knew their MDS FAB (French-American-British) subtype (ie, refractory anemia, refractory anemia with ringed sideroblasts, refractory anemia with excess blasts, refractory anemia with excess blasts in transformation, chronic myelomonocytic leukemia). Almost all patients (>95%) reported knowing they had a bone marrow biopsy to diagnose MDS, and most knew whether they had a subsequent biopsy. Three-quarters of respondents reported needing transfusions, with most patients reporting the need for repeated RBC and/or platelet transfusions. Less than one-quarter of respondents had iron chelation therapy, and the majority of these patients continue to receive chelation therapy. Repeated RBC transfusions with iron chelation therapy have a significant negative impact on QoL, second only to fatigue. Patients viewed RBC transfusions as “a necessary evil” to cope with fatigue.

The majority of patients reported that they needed antibiotics within the last month and slightly more than one-quarter had been hospitalized for treatment of infections. Nearly one-third of patients reported receiving FDA-approved or investigative pharmacologic treatments for MDS—azacitidine (Vidaza), lenalidomide (Revlimid), decitabine (Dacogen), arsenic trioxide, cyclosporine, antithymocite globulin, thalidomide (Thalomid), “other”; of these, slightly more than one-third were continuing to receive such treatments.

Patients expressed overall satisfaction with their current treatment. Slightly more than half of patients reported receiving growth factors for the management of anemia, and only 1% of patients did not know whether they had received growth factors. Of the patients who did receive growth factors, less than 10% did not know which growth factor they received. While MDS patients are relatively well informed about their disease history and current disease status, they reported having difficulty communicating with others about their disease: “My friends don’t understand what’s
A 48-year-old patient finally shared his disease with his golf foursome, and reported that 4 years later he “feels like apologizing every week that I am still alive.” Interestingly, most MDS patients participating in these forums had never spoken to another person with MDS.

**PATIENT-PHYSICIAN RELATIONSHIPS**

Responses about patient-physician relationships revealed that the majority of patients viewed their relationships with their physicians at MDS Centers of Excellence positively, whereas relationships with community physicians were viewed in a negative context owing to physicians’ lack of knowledge. (MDS Centers of Excellence are academic medical centers with clinical research and diagnostic programs in MDS. There are currently 127 worldwide.) Some MDS patients reported a lack of confidence in their physicians (general practitioners and non-hematology/oncology specialists). “I spend more time educating my doctor than anything else,” “They just don’t understand this disease,” and “Why don’t they understand this disease?” were sentiments heard multiple times at the patient forums. By contrast, nurses were viewed as key to patients’ knowledge and well being. Responses regarding patient-physician relationships shed light on a variety of barriers to effective communication, including the time constraint of doctor’s visits, lack of physician knowledge about MDS and treatment options (patients were “educating the doctor”), and physician attitudes (indifference, dismissiveness, callousness, arrogance).

As suggestions for improving patient-physician relationships, patients offered that physicians should consider not only patients’ physical condition and needs, but also should engage patients in discussions about their mental, emotional, and social well-being. Patients also suggested that more educational information and resources about patient advocacy and support groups should be provided to newly diagnosed MDS patients, as well as those who have lived with MDS for many years.

Caregivers also expressed a need for information to assist them in dealing with family and friends with MDS. In many cases these caregivers expressed significant difficulty in dealing with their loved ones’ MDS, including experiencing depression.

**CONCLUSIONS**

Only recently have we come to truly appreciate the tremendous burden of this disease and its management on MDS patients. Adult patients living with MDS have multiple physical issues with which they and their caregivers must contend—age, comorbid conditions, fatigue, dyspnea, infection, bleeding, and complications of treatments for refractory anemia—any and all of which can affect QoL. The complications of RBC or platelet transfusions—or the side effects of erythropoietin treatment, iron chelation therapy, or any of the newly available MDS therapies—take a heavy physical, psychosocial/emotional, and financial toll on patients.

MDS—the disease and its management—takes center stage in patients’ lives. MDS devours patients’ time, strength, and mental energy. It challenges patients to learn new coping mechanisms, and it affects their outlook on life, spirituality, and relationships with family, friends, neighbors, acquaintances, and strangers.

Although living with MDS can be overwhelming, and the vast majority of MDS patients describe their overall emotional status as “waiting for something to happen,” many positive changes occur in the lives of individuals diagnosed with and living with MDS.

Now that we have begun to focus more deeply on assessing QoL in MDS, qualitatively and quantitatively, we are learning how to better communicate with MDS patients and thereby improve the quality of our care. By providing MDS patients with an opportunity to explore and express their feelings and by carefully listening to their stories and responses to questions about QoL, health care providers can gain an understanding of how MDS affects individual patients on multiple levels.

Health care professionals and social scientists now have the opportunity to offer positive coping strategies to MDS patients struggling to regain the daily rhythm of their lives or to find new meaning. Continued physician education, nursing and pharmacy education, and patient education are key to improving the QoL of MDS patients. Educational programs to improve clinician knowledge and understanding of MDS, its diagnosis, pathology, management, and treatment are especially needed at the community level. Education about the impact of MDS on QoL is needed for all members of the health-care team (at the community level and at the tertiary care level).

Qualitative QoL data on MDS have only recently been collected. Clearly, there is still much that we need to learn in this area so that we can provide the best possible care to all MDS patients.

**Disclosures:**

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This special report shares information gathered in patient and caregiver forums in the US and Europe conducted by The MDS Foundation for patients and their families or caregivers.

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