

■ Article

# The Importance of Quality of Life for Patients Living With Myelodysplastic Syndromes

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Myelodysplastic syndromes (MDS) are a group of myeloid stem cell clonal disorders characterized by a wide variation in illness trajectory and potential treatment. The physical, functional, emotional, social, and spiritual well-being of individuals with MDS can be affected by both disease and treatment-related factors. As a result, the quality of life (QOL) in patients with MDS may vary throughout the course of the illness. To date, most research exploring QOL in patients with MDS has been conducted as part of clinical trials evaluating the effectiveness of a therapeutic intervention. Although data from those studies are useful, they do not fully address the issues critical to maintaining or maximizing QOL. Oncology nurses are in a key position to assist patients with MDS to maintain their QOL. Findings from comprehensive QOL assessments will guide nurses in providing relevant interventions and evaluating their outcomes. In this manner, oncology nurses can assist their patients to maximize QOL while living with this challenging illness.

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Although quality of life (QOL) is a commonly used concept, its definition is not abundantly clear. The World Health Organization ([WHO], 1997) defined QOL as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (p. 1). Within that definition, health is an important factor. WHO also defined health in a broad context as “a state of complete physical, mental, and social well-being, not merely the absence of disease” (p. 1). The definitions illustrate that, like the concept of pain, health and QOL are highly subjective, individualized, and change over time.

Myelodysplastic syndromes (MDS) are a group of highly complex diseases. For most individuals, MDS is a chronic illness; however, for others, MDS can be aggressive and ultimately fatal. Because the illness trajectory varies, the impact of the disease on QOL also differs—not only among individuals, but within individuals over time. In general, clinician focus has been on aspects of QOL that are associated with their interventions

(e.g., infection, bleeding). Therefore, other QOL domains that also are important to the patient may not be adequately addressed (Thomas, 2012) (see Figure 1). This article presents the current approaches for measuring QOL in patients with MDS, highlights some of the issues related to positive or negative effects on QOL in MDS, and identifies relevant nursing interventions to address the issues that may be of importance to patients with MDS.

## Literature Review

Research suggests that QOL is rated lower by individuals with MDS than by the U.S. general population or by those of similar age in Sweden or the Netherlands (Hellström-Lindberg et al., 2003; Jansen et al., 2003; Steensma et al., 2008). Most QOL studies specific to MDS have been conducted as part of clinical trials evaluating treatment efficacy and safety. For example, patients who were treated with decitabine therapy reported improved QOL scores when compared with those treated with growth factor, transfusion, and antimicrobial

### Physical

Decreased strength, decreased body organ function, altered immune response, diminished physiologic reserve, increased risk of developing concurrent illness, asthenia, exacerbation of other health conditions (e.g., CHF), dyspnea, bone pain and discomfort, malaise, fever, bleeding, weight loss, skin rash, symptoms from therapy, night sweats, and limited ability to adequately treat other conditions (e.g., hip replacement)

### Social

Altered role function, diminished social interaction with friends and family, diminished economic resources, diminished social network, increased financial burden from health care, time associated with therapy, activity restrictions, planning for future, transportation challenges, altered support from family and friends, economic challenges, and alteration in sexuality

### Emotional

Anxiety, loneliness, despair, uncertainty, anger and frustration, depression, communication with the healthcare team, and patient-provider relationship

### Functional

Fatigue, potential for decreased cognitive function, diminished stamina, decreased mobility, missed work associated with illness and therapy, diminished ability to perform IADLs or ADLs, diminished independence, cognitive dysfunction, and demands of illness

### Spiritual

Renewed appreciation for life, renewed appreciation for relationships, enhanced faith and beliefs, hopelessness, abandonment, loss of self, and search for balance (e.g., positive and negative aspects of life)

specific methods to measure key aspects of QOL in patients with MDS are needed.

## Quality-of-Life Issues

From a clinical nursing perspective, many QOL issues relevant to patients with MDS are inadequately addressed in the current MDS research literature. The following sections highlight some of these issues.

### Aging and Comorbidity

MDS is primarily a disease affecting older adults. The median age at diagnosis is 70–72 years (Sekeres et al., 2008). Virtually all organ functions, including the immune response, are impacted by aging. In addition, diminished physiologic reserve may result in a patient's inability to withstand a minor stressor event (e.g., developing a urinary tract infection or beginning a new medication) and, subsequently, a disproportionate decline in health develops (Clegg & Young, 2011).

ADL—activities of daily living; CHF—congestive heart failure; IADL—instrumental ADL

Note. Five quality-of-life domains are delineated here; however, other issues are not listed that may have a significant impact.

## FIGURE 1. Quality-of-Life Issues by Domain for Patients With Myelodysplastic Syndromes

Note. Based on information from Efficace et al., 2011; Steensma et al., 2008; Thomas, 2012; Thomas et al., 2005; Williams, 2006.

support alone (Kantarjian et al., 2006; Lübbert et al., 2011). Similar findings were shown for patients with MDS responding to azacitidine therapy (Kornblith et al., 2002). Specifically, patients treated with either modality reported improvement in fatigue and dyspnea (Kantarjian et al., 2006; Kornblith et al., 2002). Additional research is required to assess if QOL worsens in individuals whose disease does not respond to therapy.

Data suggest that QOL is lower in transfusion-dependent patients with MDS (Jansen et al., 2003; Pashos et al., 2011), perhaps caused by the fluctuation in hemoglobin levels seen in patients with transfusion requirements, failure to achieve normal hemoglobin levels by transfusion, or by administration of erythropoiesis-stimulating agents (ESAs) (Ritchie & Lachs, 2009). A study by Caocci, Baccoli, Ledda, Littera, and La Nasa (2007) concluded that individuals with less fluctuation in hemoglobin levels reported higher QOL ratings and less fatigue than those individuals with greater fluctuation in hemoglobin. Systematic reviews of studies exploring the efficacy of ESAs suggest that ESA use may improve QOL; however, most studies have significant methodologic limitations that preclude adequate evaluation of the significance of such improvement over time (Ross et al., 2007). The data suggest that strategies to reduce hemoglobin fluctuation may be beneficial.

Commonly used instruments for evaluating QOL in MDS are listed in Table 1, as are results from studies using those instruments. Unfortunately, many QOL studies regarding MDS have limitations (see Figure 2) and meaningful changes in QOL cannot be discerned with complete confidence. Developing

The prevalence of concurrent disease also increases with age (Ritchie & Lachs, 2009). Data suggest that patients with MDS (including low-risk disease) who have increased numbers of comorbidities have shorter survival than those with fewer comorbidities (Breccia et al., 2011; Lindquist, Danese, Mikhael, Knopf, & Griffiths, 2011; Naqvi et al., 2011).

Despite data demonstrating that hypomethylating agents can be used successfully in older adults, studies have indicated that these patients are more commonly treated with transfusion or ESA support alone (Gourin et al., 2011; Klärner et al., 2011; Pleyer et al., 2011; Seymour et al., 2010; Silverman et al., 2005). That discrepancy can result from provider bias, in which treatment decisions are based on a patient's chronological age rather than physiologic age (Kurtin, 2010). When establishing treatment goals for older adult patients with MDS, more objective data can be obtained by using a geriatric assessment tool to evaluate a patient's capability and functional status. However, increased support and care coordination often are required when treating older adults so that outcomes are optimized.

Other issues can impact QOL in older adult patients with MDS. A person's perception of health can be a significant predictor of social well-being in the older adult population (George, 2010). Receiving and providing social support also are important. Cognitive function and level of independence are key factors in one's ability to cope with the demands of illness and treatment. Therefore, the extent of social support, cognitive function, and perceptions of health may be important factors in QOL for older adults, and those factors can be adversely impacted by MDS and its treatment.

**TABLE 1. Quantitative QOL Instruments Commonly Used in Studies of Myelodysplastic Syndromes**

Instrument	Items	Domains Measured	Examples of Use
Brief Fatigue Inventory (Mendoza et al., 1999)	9	Severity, interference with function from fatigue, and presence of factors that worsen fatigue	Cross-sectional survey (N = 359). Respondents reported greater severity of overall fatigue than the control population (Steensma et al., 2008).
EORTC QLQ C-30 (Aronson et al., 1993)	30	Global QOL Physical, emotional, role, social, and overall perceived health status Symptoms: cognitive disturbance, constipation, diarrhea, dyspnea, fatigue, nausea, pain, sleep disturbance, and vomiting	Prospective randomized trial evaluating efficacy of azacitidine plus supportive care versus BSC alone (N = 191). Patients who were randomized to receive azacitidine reported improved fatigue, dyspnea, and physical functioning (Kornblith et al., 2002). Prospective randomized study comparing BSC with or without decitabine (N = 170). Patients who were randomized to receive decitabine reported improvement in fatigue and dyspnea (Kantarjian et al., 2006). Cross-sectional study (N = 407). Previously transfused patients (in the past 60 days) reported lower scores in role and social function and higher fatigue scores than those without previous transfusion (Pashos et al., 2011). Prospective study of 36 older adult patients treated with darbepoetin with or without G-CSF and transfusion. QOL scores for physical, role, and social function improved when Hgb was maintained at 12 g/dl or greater (Nilsson-Ehle et al., 2011). Prospective study of 53 patients evaluating Epo with G-CSF. Patients with a response to Epo reported greater improvement in global QOL and fatigue than those who did not respond (Hellström-Lindberg et al., 2003).
EQ-5D (Hurst et al., 1997)	6	Severity ratings of mobility, self-care, usual activities, pain or discomfort, anxiety or depression, and overall health	Prospective study at time of diagnosis (N = 841). Moderate or severe problems were found in mobility, usual activities, pain or discomfort, and anxiety or depression; health ratings were lower in older adults. Men tended to report fewer problems than women (Stauder et al., 2011). Cross-sectional study to evaluate psychometric properties of three instruments (N = 50). Only one item evaluated "own health today," and was positively correlated with Hgb level (Jansen et al., 2003).
FACT-Anemia (Cella, 1997)	FACT-G plus 20 additional items <sup>a</sup>	13 items related to fatigue 7 items related to anemia-specific concerns	Cross-sectional study (N = 359). Patients reported lower QOL ratings than the general population and reported high levels of fatigue. Fatigue ratings did not correlate with Hgb levels (Steensma et al., 2008). Prospective longitudinal study (24 weeks) evaluating efficacy of Epo (N = 53). Scores improved over time, more so in patients who responded to Epo. Scores correlated with Hgb levels (of note, subscale scores were not provided and more than 50% of QOL data were missing) (Spiriti et al., 2005). Prospective randomized study comparing the efficacy and safety of Epo with or without G-CSF (N = 30). Response (pooled from both treatment arms) were associated with an improvement in anemia subscale scores (Balleari et al., 2006).
FACT-Fatigue (Yellen et al., 1997)	13	Separate subscale of FACT designed to measure issues related to fatigue	Prospective randomized study evaluating Epo with or without G-CSF versus transfusion support (N = 102). No difference was noted between groups in scores from baseline and at four months; patients with erythroid response showed improvement in all scores at four months (Greenberg et al., 2009). Prospective study evaluating efficacy of darbepoetin with or without G-CSF (N = 44). Clinically significant improvements in fatigue scores were noted at 24 weeks (Villegas et al., 2011).
FACT-G (Cella et al., 1993)	27	Physical, functional, social, and emotional well-being	Prospective randomized study of 102 patients comparing Epo with or without G-CSF with transfusion support alone. No difference was found between groups in scores obtained at baseline and at four months; however, patients with erythroid response showed improvement in all scores (Greenberg et al., 2009).
Mental Health Inventory (Veit & Ware, 1983)	38	Anxiety, depression, emotional ties, loss of behavioral and emotional control, positive affect, total score (Mental Health Inventory Index), psychological distress subscale, and psychological well-being subscale	Prospective randomized trial evaluating efficacy of BSC with or without azacitidine (N = 191). Patients randomized to azacitidine reported improved psychological well-being over time. Patients randomized to BSC alone reported stable or worsening psychological well-being (Kornblith et al., 2002).

*(Continued on the next page)*

<sup>a</sup> The anemia subscale often is used independently, rather than combined with the FACT-G as initially designed.

BSC—best supportive care; EORTC QLQ C-30—European Organisation for Research and Treatment of Cancer Quality-of-Life Questionnaire—Cancer; Epo—erythropoietin; EQ-5D—European Quality Group—5 Dimensions; FACT-G—Functional Assessment of Cancer—General; G-CSF—granulocyte-colony-stimulating factor; Hgb—hemoglobin; QOL—quality of life

TABLE 1. Quantitative QOL Instruments Commonly Used in Studies of Myelodysplastic Syndromes (Continued)

Instrument	Items	Domains Measured	Examples of Use
Multidimensional Fatigue Inventory (Smets et al., 1995)	20	General, physical, mental, and motivational fatigue	Cross-sectional study to evaluate psychometric properties of three QOL instruments (N = 50). Physical fatigue and reduced activity subscales correlated with lower Hgb levels (Jansen et al., 2003).
SF-36® (Ware & Sherbourne, 1992)	36	Physical and social functioning, mental health, pain, role limitations (physical and emotional), vitality, and general health perceptions	Cross-sectional study to evaluate psychometric properties of three QOL instruments (N = 50). Hgb levels correlated with vitality, physical functioning, role, physical, and physical sum scores (of note, 15 of 50 patients needed assistance completing the questionnaires) (Jansen et al., 2003). Cross-sectional study (N = 26) of patients receiving chelation therapy. Scores were less than those from a large sample of the general French population (N = 3,617) for all subscales except mental health and bodily pain (Thuret et al., 2009).

<sup>a</sup> The anemia subscale often is used independently, rather than combined with the FACT-G as initially designed.

BSC—best supportive care; EORTC QLQ C-30—European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire—Cancer; Epo—erythropoietin; EQ-5D—European Quality Group—5 Dimensions; FACT-G—Functional Assessment of Cancer—General; G-CSF—granulocyte-colony-stimulating factor; Hgb—hemoglobin; QOL—quality of life

## Fatigue

Fatigue is the most prevalent symptom in patients with MDS and has an adverse impact on QOL in a myriad of ways (Steensma et al., 2008; Thomas, 2012) (see Figure 3). In a study of 359 patients by Steensma et al. (2008), fatigue was identified across all MDS subtypes. Clinically, patients with high-risk or more advanced disease often are severely fatigued. However, the fatigue experienced by patients with low-risk disease should not be minimized, particularly if it has a negative impact on the individual's QOL.

Cultural variations exist in how fatigue is defined and conceptualized (Glaus, 1998). Fatigue often is substituted by more readily understood concepts such as anemia or transfusion dependence. Anemia and fatigue ratings have correlated well in some MDS studies (Balleari et al., 2006; Spiriti et al., 2005; Stasi, Abruzzese, Lanzetta, Terzoli, & Amadori, 2005) but not in others (Meyers, Albitar, & Estey, 2005; Steensma et al., 2008; Thomas, Zhang, & Greenberg, 1999). Therefore, current evidence is inadequate to support the use of anemia or transfusion dependence as a surrogate marker for fatigue.

Physical aspects of fatigue often relate to weakness, tiredness, and dyspnea. However, from the patient's perspective, the impact of fatigue on one's functional ability often is more important (Steensma et al., 2008; Thomas, 2006). Fatigue-related functional deficits, including cognitive deficits, may force early retirement from employment. Although potentially problematic at any age, retirement may have more severe impact on QOL in younger patients with MDS who have inadequate time to prepare financially, emotionally, and socially.

The added burdens associated with both disease monitoring and treatment (e.g., medication management, office visits, transfusions, side-effect assessment) may usurp a patient's limited energy stores and interfere with fulfilling other roles (work, social, and familial). Those effects can be particularly detrimental for patients who live alone or lack adequate social support. Patients with affective fatigue may be reticent to consider interventional therapies that require a high degree of patient participation or that carry significant or unknown risk of side effects.

Cognitive fatigue can present a significant impediment to therapy by affecting a patient's ability to understand potential complications of disease or treatment. Patients may not adequately comprehend what is expected of them in terms of medication management and treatment schedules (MacLaughlin et al., 2005), particularly when instructions are verbally rushed, written in an unfamiliar format using medical jargon, or not provided within a context in which the patient functions or relates. In addition, cognitive fatigue can adversely impact short-term memory, the ability to perform instrumental activities of daily living (e.g., paying bills), and the ability to fully engage in social relationships.

## Uncertainty

The psychological impact of MDS can be considerable for many patients. Any illness experience can result in a state of uncertainty, which can affect psychosocial adaptation and disease outcome (McCormick, 2002). Mishel (1988) defined uncertainty as the "inability to determine the meaning of illness-related events" (p. 225), and noted that a person may view the situation as negative (dangerous) or positive (an opportunity).

Sources of uncertainty vary in the MDS illness trajectory. Initially, uncertainty can result from the disparity of having a life-threatening illness that manifests with only mild, if any, symptoms (Thomas, 2006). Throughout the course of illness, inadequate understanding of the disease process, inability to anticipate its probable trajectory, and difficulty choosing the most appropriate therapy all contribute to heightened uncertainty (Latsko, 2011; Thomas, 2006). That uncertain illness trajectory challenges patients with MDS to find meaning in the disease process and to develop effective coping behaviors (Latsko, 2011). Key to developing successful coping mechanisms is the patient's relationship with the healthcare team.

## Nursing Interventions to Maximize Quality of Life

Nurses are intimately involved in the care of patients with MDS on many levels and often are the first point of contact for

patients. Current research typically addresses the physical domain of QOL. Too often, the functional, emotional, social, and spiritual aspects of QOL are inadequately addressed. Nurses can use several strategies to assist patients struggling to cope with their illness. Comprehensive evaluation using validated assessment tools, provision of interventions supported by research, continuous re-evaluation, and use of a holistic approach are required to address the needs of this patient population (see Figure 4).

## Communication

Patient-practitioner communication is an integral component in the QOL of patients with MDS. Initiation of effective communication should occur at the patient's first clinic appointment and be cultivated with subsequent appointments to ensure that an adequate patient-practitioner relationship develops. Several patient-practitioner barriers can influence the development of this relationship (see Figure 5). Effective communication requires encouraging patients and caregivers to ask questions and engage in shared decision-making. Patients should be encouraged to report any psychological, emotional, physical, or functional effects of their disease, treatment, or underlying illnesses so that the practitioner is fully aware of how the patient's QOL is impacted in all dimensions.

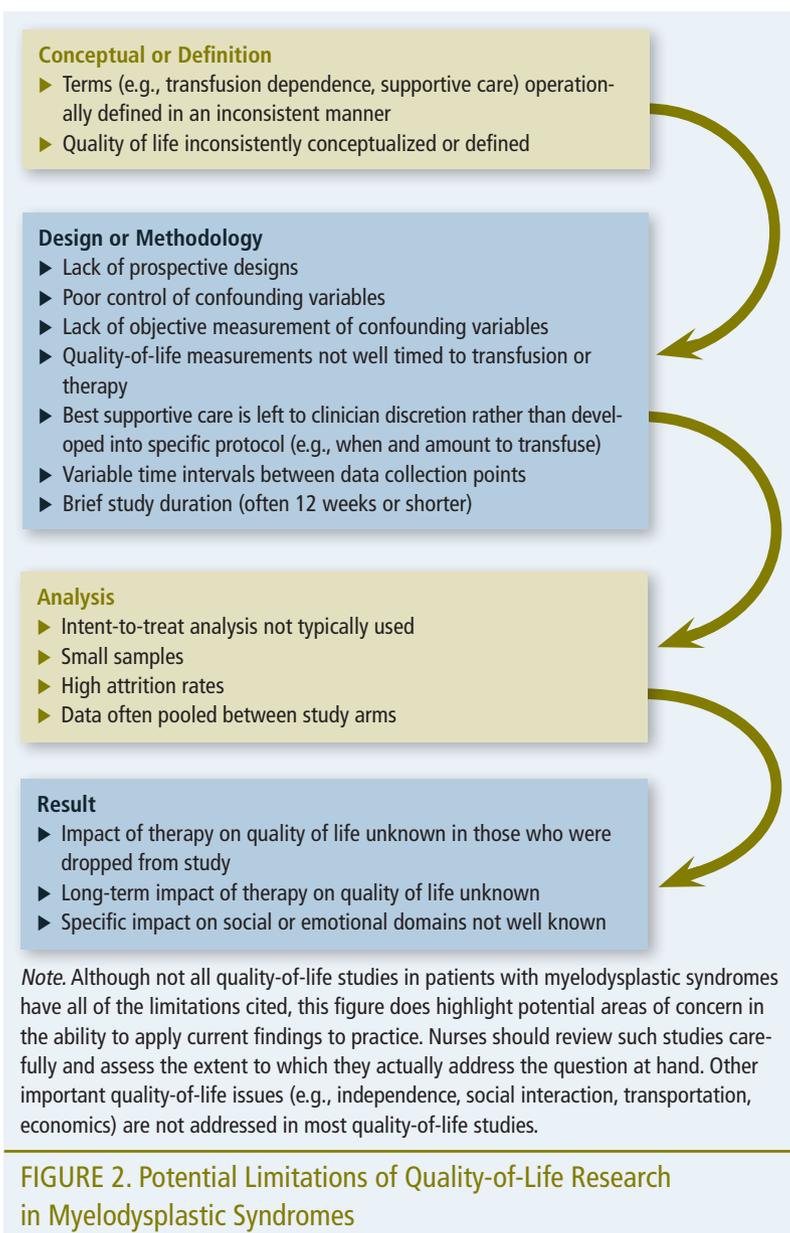
## Physical Issues in Quality of Life

Within the physical domain of QOL, many issues may require intervention. Dyspnea is a distressing symptom that often is aggravated by anemia, infection, and comorbidities such as congestive heart failure. The consequences can be debilitating, contributing to fatigue and depression, and may prevent patients from participating in activities (Martelli-Reid et al., 2010). Unrelieved dyspnea also may result in anxiety. Regular assessment of oxygen saturation and respiratory status is important because some patients may require supplemental oxygen. Depending on the patient's age and underlying cause of dyspnea, more frequent transfusions (using fewer units) of red blood cells may help reduce fluctuations in hemoglobin levels, thereby improving anemia, dyspnea, and fatigue. Assessing fluid status and avoiding excess infusions can help reduce the burden of volume overload. Teaching relaxation and deep-breathing exercises as well as encouraging patients to modify activities (e.g., by sitting or using assistive devices) also are useful strategies. Compared to patients with lung cancer who were provided standard management, these behavioral interventions (combined with psychosocial support) resulted in reduced breathlessness, improvements in QOL (physical and emotional), and improved performance status in patients with MDS (Ream, Pallister, & Clarke, 2004). The data suggest that the education and support provided

by nurses makes a substantive difference in the severity of experienced symptoms.

Pain can have a dramatic effect on QOL—the effect appears to be greater when it results from cancer than from other causes (Ream et al., 2004). In patients with MDS, pain can result from splenomegaly, bone, skin and soft tissue infections, or medication injection sites. Generally, pain medications are provided in a stepwise approach as recommended by the WHO (1996). However, patient adherence to the prescribed regimen may vary because of side effects, concern about addiction, or lack of understanding regarding medication self-administration. Nonpharmacologic techniques also can be effective adjuvants to manage pain (e.g., positioning, massage therapy, aromatherapy, thermal measures, mind-body therapies) (Gatlin & Schulmeister, 2007). If the nurse is not trained in these therapies, referral to an integrative provider should be considered.

Bleeding can cause significant distress in patients with MDS. Managing this disturbing complication should include advising the patient in advance so that he or she is mentally prepared



**FIGURE 2. Potential Limitations of Quality-of-Life Research in Myelodysplastic Syndromes**

for its occurrence. Avoiding constipation, contact sports, use of heavy machinery, and the use of electric razors, as well as performing gentle oral care, all are recommended. Keeping nasal passages moist and free from trauma may help prevent epistaxis. Assessing the patient for signs of hematuria, hematemesis, rectal bleeding, bruising, purpura, and petechiae should be part of a routine physical assessment (Pereira, 2008). Aggravating factors to consider might include vitamin K deficiency, liver dysfunction, alcohol abuse, or nonsteroidal anti-inflammatory drug use.

Fevers, night sweats, weight loss, rashes, and other treatment-related symptoms also can affect the QOL of patients with MDS. Inadequate nutrition is a confounding factor to be considered. Patients should be regularly weighed and provided with early dietary intervention. Strict neutropenic diets should be replaced with advice on food safety, allowing patients the satisfaction and enjoyment of “comfort foods.” Surgeries, dental work, and other invasive procedures often need to be canceled or undertaken with intense planning and preparation. Many patients are unable to tolerate the risks involved with such procedures because of the increased risk of infection or bleeding. In addition, the exacerbation of other health conditions, such as congestive heart failure, can be frustrating. Nurses can help alleviate such issues by facilitating communication among practitioners; advocating for their patients; and identifying, assessing, and addressing physical impacts on QOL.

### Functional Issues in Quality of Life

Fatigue is common in patients with MDS, is often multifactorial, and is a prominent factor in QOL (Armour, Pallister, & Howells, 2004). Interventions should target the etiologies involved. Depression, pain, sleep disorders, deconditioning, anemia, fluid or electrolyte imbalances, hypoxia, infections, hypogonadism, or polypharmacy can contribute to the severity of fatigue. The most effective strategies for fatigue management include exercise, adequate sleep, social interaction, and “doing something different,” suggesting that distraction is useful (Graydon, Bubela, Irvine, & Vincent, 1995). Patients with fatigue may find exercise unrealistic; however, research has shown that daytime inactivity increases fatigue levels (Visovsky

#### Physical Fatigue

Decreased physical performance, decreased strength, weakness, unusual need to sleep or rest, unusual tiredness, or sleep disturbance

#### Affective Fatigue

Loss of motivation, decreased stamina or lack of energy, sadness, anxiety, and “no fighting spirit”

#### Cognitive Fatigue

Decreased ability to concentrate, difficulty thinking, and “tired head”



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### FIGURE 3. Multidimensional Nature of Fatigue

Note. Based on information from Glaus, 1998; Steensma et al., 2008; Thomas, 2012.

## Implications for Practice

- ▶ Quality of life (QOL) is a complex, individually defined, and fluid state for patients living with myelodysplastic syndromes (MDS), and includes physical, social, emotional, functional, and spiritual domains.
- ▶ Aging, comorbidities, fatigue, and uncertainty play important roles in QOL for patients with MDS.
- ▶ Oncology nurses are in a key position to assist patients with MDS to maintain their QOL through systematic assessment, referrals, and ongoing support.

& Schneider, 2003). Cimprich (1993) suggested that activity be at a modest pace for about 20–30 minutes, two to three days per week. Patients may be referred to their provider for evaluation for antidepressants, analgesics, ESAs, or psychostimulants. Importantly, fatigue is a complex, common complication of MDS; nurses have the opportunity to educate their patients and assist them in establishing reasonable expectations.

### Emotional and Spiritual Issues in Quality of Life

Patients with MDS are known to be at risk for depression, which occurs in 10%–22% of patients with cancer (Ream et al., 2004). Anxiety and fear of future complications can be overwhelming for some patients. Most patients fear the potential progression to acute myeloid leukemia, independent of their actual risk for the progression. However, some patients will view their diagnosis as an opportunity to enhance their faith and might express a renewed appreciation for life and relationships (Thomas, 2012). Others might experience hopelessness and abandonment. Anger can be directed toward family, friends, or the healthcare team.

Unfortunately, assessing psychological status often comes only after addressing physical issues, leaving many patients without adequate psychological support (Latsko, 2011). Consistent and accurate information, anticipatory guidance, and clear and consistent communication can be useful in diminishing uncertainty and anxiety. The nurse can encourage the patient to express positive experiences through reminiscence and life review. Written information on spiritual or psychological resources can be provided. If the patient expresses a desire for counseling, the nurse should make appropriate referrals to psychiatric or spiritual professionals. Local support groups can be excellent resources and a source of reassurance for patients with MDS. In clinical depression or anxiety, the addition of antidepressants or anxiolytics may be useful.

### Social Issues in Quality of Life

Living with MDS can render the patient at risk for social isolation. Being told they are at risk for infection may result in individuals removing themselves from social interactions. Some people avoid their pets or tasks such as gardening that once provided fulfillment. Although infection-prevention education is important, patients also need to be encouraged to find safe ways to maintain normal activities and routines as much as possible. For example, rather than removing a pet from the

home, the nurse might advise the patient to recruit others to handle the animal's excrement.

The sheer amount of time required for repeated blood work, infusions, and clinic visits significantly interferes with time for other activities, including work and social interaction. Infusion devices, fatigue, and the fear of infection can adversely impact sexual activity. Asking relevant questions in a nonthreatening and open manner can help initiate dialogue about sexuality issues (Richards, Berlotti, Doss, & McCullagh, 2011).

The financial strain from treatment can be significant for patients with MDS. A Cancer Support Community (2010) study found that 81% of patients experienced moderate to severe stress levels from monetary burdens associated with cancer care. Those findings were corroborated in Canada where a "sizeable minority of cancer patients find the burden of out-of-pocket costs to be significant or unmanageable, even in a healthcare environment where much of the care falls within the public funding envelope" (Longo, Fitch, Deber, &



**FIGURE 4. Nursing Interventions to Maximize Quality of Life According to Domain**



### Patient Barriers

- ▶ Age
- ▶ Gender differences
- ▶ Racial or cultural differences
- ▶ Beliefs and attitudes regarding care
- ▶ Misinterpretation of medical language and terminology
- ▶ Psychological or emotional distress
- ▶ Chronicity of the disease
- ▶ Unmet informational needs regarding the disease and treatment
- ▶ Difficult to discern between reliable and unreliable sources of information

### Practitioner Barriers

- ▶ Academic versus community practitioners
- ▶ Limited exposure to patients with MDS
- ▶ Appointment time constraints
- ▶ Attitudes toward patients
- ▶ Knowledge deficit regarding MDS and treatment
- ▶ Poor or confusing explanation of MDS and treatment
- ▶ Concentration on physical needs of the patient; less focus on emotions



MDS—myelodysplastic syndromes

## FIGURE 5. Barriers to Effective Communication

Note. Based on information from Protière et al., 2011; Rodin et al., 2009. Images copyright 2012 by iStockphoto.com/Dan Tero. Used with permission.

Williams, 2006, p. 1082). Threats to one's identity and altered role function can interfere with QOL. Younger adults may resent having to ask for assistance with childcare. Married couples can find themselves being defined as "patient" and "caregiver."

Improved QOL often is a key reason for developing home treatment programs. Crisp (2010) reported that patients described receiving cancer care at home as being in a "natural habitat"—a place in which they were better able to cope with the circumstances surrounding their illness. Those patients actually viewed themselves as being less ill. Some centers facilitate obtaining blood specimens or even administering chemotherapy and transfusing blood products in the home. Given the palliative circumstances surrounding the care of many patients with MDS, treatment at home should be considered when possible.

## Palliative Care

QOL is the core of palliative care, from the time of diagnosis of a life-threatening illness to the last days of life. Within this palliative approach, maintaining QOL requires active disease management, symptom control, and support for the entire family unit. Healthcare providers should proactively determine when a patient is experiencing a decline in any QOL domain throughout the disease trajectory to allow effective management and to maximize QOL.

No literature is available on QOL measurement within end-of-life care in patients with MDS; however, the end-of-life care experience for patients with hematologic illnesses and their family members was examined by McGrath (2002). Data suggest that many patients have died on busy general wards following an emergent admission while being cared for by teams who were unfamiliar with the patient and after enduring invasive diagnostic procedures. Globally, this situation may not be the case for patients with MDS because many are cared for by the same teams of healthcare professionals for years. However, the longitudinal nature of this relationship may contribute to

a hematology team's own emotional struggle when long-term patients enter into the end-of-life phase of their illness trajectory (McGrath & Holewa, 2006). Healthcare providers may have difficulty determining when the patient is moving into the end-of-life phase because clinical indications can be masked by comorbidities, frailty, and general poor performance status. However, McGrath and Holewa (2007a) suggested that clear clinical indications of progressive disease exist and that they require a change in care focus, such as the clinical benchmarks of increasing symptoms and the need for more transfusion support.

McGrath and Holewa (2007b) developed an end-of-life care model in which the priority is on quality rather than quantity of life. Key concepts to maintain or enhance patient QOL are open and honest communication, balancing hope and reality, and adequate pain control. Symptom management, with a special emphasis on providing blood product support and, when appropriate, preparing for a catastrophic hemorrhage, is crucial. Introducing clear criteria for patient referral to palliative care based on need for symptom management and psychological support helps ensure that the palliative care team is integral to the hematology team. Early referral to palliative care enables the patient to develop a solid relationship with this team before transitioning to end-of-life care. If the patient or family has difficulty transitioning care, the palliative care team can support the hematology staff by advising on symptom management and managing sensitive situations (Hicks, 2003).

## Conclusions

MDS is an all-encompassing term for a group of complex disease states with highly variable illness trajectories. The resultant impact on an individual's QOL also is complex and variable. Nurses are in a critical position to monitor the multifaceted impact of illness and treatment on patients' QOL. Nurses also are pivotal in providing interventions to assist patients in maximizing their QOL while living with these challenging diseases.

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