The Impact of Myelodysplastic Syndromes on Quality of Life: Lessons Learned from 70 Voices

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ABSTRACT

Background: Little is known about the impact of myelodysplastic syndromes (MDS) on the quality of life (QOL) of those living with the disease.

Objectives: The purpose of this qualitative study was to explore this phenomenon.

Methods: Seventy patients with MDS participated in five focus groups conducted throughout the United States. Transcripts from recordings of focus group sessions were coded and emerging themes identified using thematic analysis.

Results: Findings revealed a multifaceted description of how MDS affects QOL. MDS was found to cause a substantial and sustained decrease in ability to function. QOL was adversely affected by work expended on managing the disease. The emotional impact was often viewed as more problematic than the physical impact; emotional reactions included shock, anger, depression, and anxiety. In contrast, spiritual well-being was often enhanced, with a renewed appreciation for life, relationships, and faith.

Conclusions: Data from this study suggest that MDS has a substantial, often negative impact on patients' lives and clinicians should be cognizant of this impact. Attention must be directed at providing more comprehensive support for the patient throughout the illness trajectory.

Limitations: The method of subject recruitment may have limited participation to individuals who are more proactive in obtaining information about their illness. The focus groups convened only once; thus, purposive sampling and repeated assessments were not possible.

Myelodysplastic syndromes (MDS) are a heterogeneous group of clonal stem cell disorders resulting in chronic cytopenias. The impact of MDS on an individual's quality of life (QOL) is not well understood. Historically, QOL was often conceptualized in a rather limited scope in this patient population as extent of anemia or infection, rates of disease evolution to acute myeloid leukemia, and overall survival.[1]

QOL is actually a highly complex concept, one that is largely culturally based yet still highly individualized and dynamic. Health-related QOL (HRQOL) is an important component of one's total QOL and is defined as "the value assigned to duration of life as modified by impairments, functional states, perceptions, and social opportunities, and as influenced by disease, injury, treatment, or policy."[2] Several domains exist within the HRQOL construct: physical, functional, social, emotional, and spiritual well-being.[3–7] QOL can be significantly altered, particularly as one's health and life are impacted (either positively or negatively) by illness and/or treatment.

The majority of QOL studies in MDS patients are secondary objectives in clinical trials evaluating the efficacy of growth factors.[8–13] Data suggest that those patients who demonstrate a response to treatment show an improvement in QOL. More recent studies demonstrate an improvement in QOL in patients treated with decitabine compared to those treated with growth factor, transfusion, and antimicrobial support alone.[14,15] Similar findings were noted in a study where patients receiving azacitidine indicated a significant improvement in fatigue and physical function.[16] However, findings from these studies were limited by short length of follow-up,[8,11] high attrition rates,[10,13–16] or lack of QOL assessment at the time of complication or withdrawal from the study.[15,16] Thus, the potential negative impact of MDS treatment on QOL is not well known.

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Table 1

Demographic Characteristics of the Focus Group Sample (n = 70)

	MEAN	SD
Age (in years)	69	9
Education (in years)	14.6	3.3
	Median	Range
Time since MDS diagnosed (months)	26.5	3-276
	%	
Gender		
Female	49	
Male	51	
Marital status		
Married	65.7	
Widowed/divorced	28.6	
Other	5.7	
Living Alone	26	
Employment		
Retired	64	
Work full time	14	
	n	%
Site of focus group		
Chicago, IL	16	22.9
New York, NY	11	15.7
Palo Alto, CA	18	25.7
Scottsdale, AZ	14	20.0
Tampa, FL	11	15.7

Table 2

Disease, Treatment, and Concurrent Illness Demographics[a]

MDS subtype	
RA	27%
RARS	27%
RAEB	16%
5q-	4%
Other	3%
Unknown	23%
Concurrent health problems	68.6% (63/70 responses)
Coronary artery disease	21.4%
Muscular–skeletal disorder (excluding arthritis)	21.4%
Cancer	15.7%
Arthritis	14.3%
Endocrine disorder (excluding diabetes)	10.0%
Vascular disease	8.6%
Diabetes	7.1%
Ear–nose–throat disorders	7.1%
MDS therapy	
Growth factors	69%
Transfusion	61%
Antibiotics	57%
Azacitidine	19%
Thalidomide	16%
Lenolidomide	7%
Iron chelation	14%
All other	23%

RA, refractory anemia; RARS, refractory anemia with ringed sideroblasts; RAEB, refractory anemia with excess blasts.

[a] The specific MDS subtype, concurrent health problems, and therapy were identified by the participants, not by medical record review.

Less is known about how MDS itself impacts an individual's QOL. MDS patients demonstrated lower median QOL scores when compared to those from a representative sample of Americans[17] or to a sample of the Dutch[18] and Scandinavian[12] populations matched for age and gender. Fatigue is a significant problem in the MDS patient population[17–21] and is not consistently well correlated with hemoglobin levels.[17] One report of MDS patient educational forums suggests that the illness as well as treatment do indeed impact a person's QOL.[22]

Data obtained from these studies suggest that MDS may have a negative impact on an individuals' QOL, and successful treatment of the disease may afford an improvement in QOL. Yet, these data do not provide a detailed depiction of the specific QOL issues that confront individuals living with this illness. Qualitative research provides the opportunity for such description.[23]

The purpose of this study was to explore how MDS impacts the QOL of those living with the disease. Five focus groups convened throughout the United States over a 5-month period. With one exception, all focus groups were held at sites away from a health-care institution.

METHODS

Sample

Patients were recruited from a posting on the International MDS Foundation Web site. Seventy patients participated in the focus groups; all signed institutional review board (IRB)–approved consent forms. Family members often attended as well; however, as IRB approval was not obtained for family participants, their comments were excluded from the analysis. The sample was evenly distributed by gender; most were Caucasian. Patients ranged in age from 35 to 83 years and were well educated (see Table 1).

The majority of patients were able to identify their specific MDS subtype (French–American–British [FAB] classification). MDS was not an isolated health problem; over two-thirds of the participants reported at least 1 additional concurrent health problem. Almost 16% reported having had a prior cancer diagnosis, suggesting that some of the patients may have had MDS resulting from prior chemotherapy (see Table 2).

With one exception, participating patients were not new to having MDS (range 3–276 months since diagnosis). Over half of the patients had received transfusion support, primarily packed red cells. Almost 75% had received growth factors, primarily some form of erythropoietin; 1 out of 3 of patients had received granulocyte colony-stimulating factor (G-CSF).

Azacitidine was the most common other type of MDS treatment used by these patients. Despite the fact that many patients had participated in clinical trials, other therapy was infrequently used.

Many of those attending the focus groups volunteered that this was the first time they had met someone else with MDS face to face. Many also admitted that they came to the focus group with trepidation, apprehensive of what they might encounter as they met others with the same illness. In contrast, one of the focus groups included several members of a patient-led MDS support group.

Procedure

The focus groups invited an open-ended discussion of how MDS impacts QOL based on Ferrell's work exploring the impact of cancer on QOL.[5] Each of the focus groups was led by a hematology clinical nurse specialist, with expertise in the care of the MDS patient population and interest in QOL issues. Given the exploratory nature of the study design, the discussions proceeded in different directions; but core questions were asked at each session. Participation was encouraged but not forced, and 89% of patients actively participated in the discussions. Sessions were audiotaped, professionally transcribed, and aided by N5™ qualitative software (QSR International, Cambridge, MA), coded using content analysis methods.[24] Using the QOL conceptual frameworks by Ferrell[5] and Cella et al,[4] the coding was then categorized using the domains of physical, functional, emotional, social, and spiritual well-being to gain better insight into how MDS impacted each of these QOL domains. The analysis was independently repeated, results were compared for consistency, and discrepancies were resolved. Table 3 details the most commonly described themes within each of the QOL domains.

RESULTS

Physical Well-Being

Despite its emphasis from the medical community, many focus group participants felt MDS had little impact on their physical well-being. For some, the symptoms of severe anemia led to a diagnosis of MDS, such as difficulty climbing stairs and dyspnea on exertion. Yet, for many, symptoms were initially either vague or nonexistent. Side effects of treatment often caused a poorer QOL and included pain (often associated with injections, including G-CSF), nausea, fatigue, fevers, malaise, and asthenia. One patient described his experience with treatment: "By day 2 or 3, I was almost bedridden in terms of the pain and the swelling that came with [treatment]."

MDS adversely affected a person's physical well-being by circumventing appropriate treatment for other health conditions (eg, hip replacement, cataract removal, and even dental extraction). The consequences of such circumvention potentially encompassed all QOL domains, based on the actual condition and treatment needed (but unattainable due to MDS).

Table 3

Common Themes from Focus Group Discussions

Physical well-being	
Symptoms related to anemia	24%
Symptoms related to treatment	21%
Functional well-being	
Decreased ability to function	37%
Fatigue	39%
Work associated with administering therapy	24%
Work associated with interpreting and managing symptoms, side effects, and complications	29%
Work associated with office visits	32%
Social well-being	
Activity restrictions	16%
Time associated with office visits	32%
Relinquishing roles	13%
Planning for future	18%
Emotional well-being	
Shock at diagnosis	10%
Anger and frustration	16%
Depression	25%
Anxiety and fear	29%
Uncertainty	42%
Spiritual well-being	
Renewed appreciation for life	8%
Renewed appreciation for relationships	10%
Enhanced faith and beliefs	13%

Themes most commonly discussed by participants and the frequency of their occurrence. Note that each participant could describe more than one theme within each domain. Several participants referred to the theme more than once during the group discussion. See text for exemplars of each theme.

Social Well-Being

MDS had a negative impact on an individual's social well-being. Patients in these focus groups did not describe the positive benefit of social support beyond that of their spouse and/or adult children. Friends and acquaintances were often described as more burdensome than supportive, largely stemming from a lack of understanding and interest in the MDS disease process. Ambiguity in one's social roles subsequently resulted and, for many patients, merely because the patient did not appear seriously ill. One patient advised, "Don't tell people what you've got because they don't know what you're talking about. All it's going to do is cause you more aggravation than it's worth."

Lack of understanding made it difficult for patients to express their feelings and concerns regarding their illness with others. While some family members provided extensive social and emotional support, this was not the case for all. Some patients described feeling more isolated due to the inability to confide in their spouse.

As would be expected, fatigue interfered with patients' ability to function socially. But other sequelae from MDS also interfered. Thrombocytopenia limited some patients from physical and recreational activity; neutropenia prevented

many patients from air travel—either for long-planned vacations or simply to visit grandchildren.

Functional Well-Being

The impact of MDS on functional well-being varied widely in this sample. For many, it had little negative impact, yet for others the impact was significant and severe. One patient described MDS as "a deterioration of what you were able to do before." Fatigue was often a significant cause of functional decline. As one patient described, "you start realizing how much energy means to everything . . . as you lose energy, you lose everything else with it." Fatigue also impaired patients' motivation to be engaged with living their lives, as described by one participant: "I don't have any severe symptoms except that I'm not really living my life . . . every day [I'm] finding excuses not to do things."

Living with MDS caused a significant decline in one's ability to maintain preexisting roles within family and work, often with far-reaching impact. One participant was concerned about the economic consequences of her inability to physically care for her grandchildren. Family members were now forced to take on additional roles and functions previously held by the patient, such as household chores, responsibility for family finances, and working outside the home. They also acquired new roles and functions related to managing the patient's illness and treatment—often without assistance from the health-care system. This role shift often caused significant stress on relationships, particularly if the patient was younger. One patient, only 53, reported he could only perform 1–2 hours of physical work/day around the home and described the frustration felt by his wife: "Oh—, I'm working all day and all week and you don't get anything done around the house."

Many patients described another new role for them, that of patient advocate. For some, it was a conscious decision to become fully engaged in their health care; for others, it evolved from frustration with their physician's apparent disinterest or inability to competently care for them. Some patients experienced a decline in their determination to advocate for themselves, as reflected in one person's assessment that "MDS weakens your ability to stand up and respond." Many patients actively investigated new treatment options, while others actively sought new physicians who were more familiar with the disease process. The amount of time and energy required to perform these functions was extensive. One patient reported that he quit working, simply because he was spending so much time seeking information and treatment options.

Patients found themselves responsible for educating themselves—and health professionals—about MDS and were frustrated with this added responsibility. "Most doctors don't know what you're talking about . . . . You have to educate your [other] physicians, your dentist, and it's a problem."

Even those who were not as active in seeking out treatment options were expending considerable work at monitoring their disease, evaluating symptoms and treatment side effects.

One patient described the difficulty as "you don't know whether it's the disease causing something or the medication causing something, or if it's something else." In the setting of fragmented, specialty care, patients were forced to make a judgment about the source of their symptom or problem, so that the "correct" specialist would be notified. For example, if a patient developed shortness of breath, he or she needed to discern the etiology as being worsening anemia (and contacting the hematologist) versus being worsening congestive failure (and contacting the cardiologist).

Emotional Well-Being

Patients' emotional well-being was adversely impacted by MDS. The diagnosis of a chronic, yet poorly understood disease generated significant anxiety for many. The uncertain nature of the illness trajectory, difficulty interpreting symptoms within the context of other comorbid conditions, and the perception of indifference or ineptitude from health-care providers all caused anxiety. "What's my hemoglobin? What are my blasts? It takes a big toll on the emotions." This anxiety was manifested in a variety of ways, including sleep disturbances, difficulty concentrating, and fear.

"Fighting the system" was a significant source of anxiety, frustration, and depression. For many patients, the "system fights" related to health insurance. Financial burden (expensive treatments, time lost from work, or loss of work itself) was extremely stressful. One patient angrily described her family's struggle to survive on 1 income now that she was unable to work. Another described her concern about being able to continue to work, the source of her family's insurance benefits. For others, fighting the system related to health-care delivery services. The ordeal related to receiving erythropoietin injections in physicians' offices, and particularly, receiving transfusions was depicted by many as inefficient and burdensome, a perpetual source of frustration. For others, these procedural barriers resulted in confusion and simply feeling overwhelmed.

For many patients, the greatest impact of MDS on emotional well-being resulted from significant depression. Many found activity restrictions a source of depression—as were the functional impairments rendered by disease and treatment, described by one participant as the loss of the "ability to do what I want to do." Another woman described her reaction to her limited function: "My balance isn't what it should be . . . . I'm 55. I look at these people who are like 85 years old and they're out running around the block and that can bring you down a bit." Others found the "fatal" nature of the illness to be a significant cause of depression. Several patients described the impact of viewing cancer patients, either in the clinic waiting room or in the infusion centers. While their initial reaction was often one of anxiety ("will this happen to me?"), some described the cancer patients' courage as inspiring yet admitted it was nonetheless depressing to witness.

While physicians' lack of information caused anxiety and frustration for some, it was a source of depression for others, thwarting the patient's attempts at establishing or maintaining hope. Patients found the lack of informational resources frustrating and took it upon themselves to research symptoms and side effects. However, as one patient pointed out, "your imagination starts to take over," in large part from the lack of a contextual reference for interpreting symptoms.

For many, the diagnosis of MDS brought with it a realization that one's dreams and plans for the future would not be fulfilled, resulting in reactions that varied from anger to depression. While independent of the patient's age at the time of diagnosis, the severity of the reaction appeared greater in those who were younger. One woman described the emotional impact as the worst aspect, wishing she did not have three young sons to "leave behind."

Spiritual Well-Being

For those who described MDS having an impact on spiritual well-being, it was generally positive. Several patients described a resultant reprioritization of what was important in their lives and relationships since having MDS. One patient described this as "a blessing in that you really look at what's important in your lives, in your family, that type of thing and I think it brings you closer together . . . . It may be family, it may be resolving things, but in a weird way, there's a blessing underneath."

Others described a strengthening of their preexisting faith and the benefits received from others by prayer and support. One participant described making peace with the fact that there is (as yet) no cure for most with MDS. Still others described a change in their attitude, learning to appreciate what they had and to make the most of every day. One man reported, "The most helpful thing that was said to me about this disease was said by a Zen master . . . 'practice gratitude.' And that has worked."

While an enhanced relationship with God was voiced by many, that relationship could still have a negative impact on QOL. For one patient, extensive stress restricted her ability to worship: "I'm an avid, strong Christian, and I didn't want to get out of bed. I didn't want to go to church . . . . How can [MDS] not cause emotional, along with spiritual—who wants to get out of bed? I love you God—I'll listen to the radio."

Another significant, negative impact on spiritual well-being was the persistent struggle to find meaning in one's illness. This difficulty was often seen in those individuals who were told their disease was serious but who did not appear ill. One patient described seeing her physician after returning from vacation and being told he was referring her to hospice because "it was that serious." Several patients rationalized this difficulty by comparing themselves to others with more severe or life-threatening conditions. Others viewed it as a "wake-up call," a time to reprioritize what was truly important in their lives.

Uncertainty

For many, living with MDS meant living with sustained uncertainty. Uncertainty was manifest in many ways, each providing a negative impact on QOL. It was exemplified in patients' difficulty interpreting symptoms and life expectancy. "Each time another symptom occurs, you wonder why this is happening or what's going to happen. Is it going to get worse? What's going to happen next week when another symptom comes?"

Uncertainty can stem from a lack of explanation about the disease process and clinic routines. "When I was first diagnosed, they kept sending me to the cancer center, and I was thinking, 'Do they think I have cancer?'" For others, uncertainty stems from viewing other patients: "When I see the other people [in the waiting room], I think does this sickness lead to that or what?"

Coping with uncertainty was particularly true for those who had significant health problems previously—heart disease was managed by bypass surgery; cancer was treated by surgery and/or chemotherapy. Such interventions were viewed as concrete and known measures to correct a problem. The same concrete approach did not apply to MDS, and participants had difficulty with this difference, particularly when their physicians did not demonstrate confidence in how best to manage the disease.

Uncertainty had a significant impact on one's social well-being, often causing difficulty planning for the future. This difficulty could be depicted in small ways, such as the inability to predict feeling well enough to attend a family function, or in larger ways, such as struggling to decide if one should relocate closer to one's children, thereby transferring care to an unknown physician, who was potentially inexperienced in managing MDS. Others described difficulties with financial planning: "I don't know whether I ought to be dispersing [my funds] to my children now because death is imminent; I don't know how imminent."

Perhaps the greatest impact of uncertainty lies within the spiritual well-being domain. One subject succinctly described this impact: "It's very troubling to have Damocles' Sword swinging over your head and not knowing how to plan the rest of your life, however long it's going to be."

LIMITATIONS

This study has several limitations. First, the method of subject recruitment may have limited participation to individuals who were more proactive in obtaining information about their illness. Moreover, the focus groups convened only once; thus, purposive sampling and repeated assessments were not possible. The large size of the focus groups may have restricted some patients' participation and restricted the leader's ability to ask more probing questions, thereby limiting the type of data analysis performed. In addition, family members often attended, potentially affecting patients' willingness to speak candidly about QOL issues (eg, family relationships, sexuality). Finally, as a whole, the sample's educational level

and upper-/upper middle-class socioeconomic status could be a significant factor in QOL assessment.[25]

DISCUSSION

As a disease state, MDS poses unique challenges for those who live with it. Due to the heterogeneity of the disease, the illness trajectory is quite variable, often confounded by a myriad other factors, such as physiological age, functional status, and comorbid conditions.[20,21,26–28] Thus, clinicians may be reticent to recommend aggressive treatment. Focus group participants indicated they did have other health conditions beyond MDS. Yet, with few exceptions, the majority of these patients perceived themselves to be quite healthy and, thus, able to "handle" the rigorous nature of intensive treatment.

Many clinicians may not have adequate expertise in the management of this complex illness. Clinicians' lack of confidence often resulted in more work for many focus group participants: searching out information related to treatment options (and where that treatment is available), monitoring response to treatment, and coordinating care between multiple providers. The burden of this work can adversely affect one's emotional well-being but also one's social well-being. Some patients actually retired so that they could devote more time and energy to monitoring their disease.

Fatigue is a highly complex, subjective, and multidimensional phenomenon.[22,28] Fatigue encompasses feelings of physical weakness, lethargy, decreased mental alertness, and diminished concentration.[29,30] In the context of chronic illnesses, fatigue is unrelenting and interferes with one's ability to function normally. While anemia is absent from these descriptions, it is frequently (and often inappropriately) used as a surrogate marker of fatigue. Focus group members described the fatigue they experienced as a lack of energy and a marked decrease in ambition, stamina, and motivation to perform normal activities.

Transfusion support remains a primary therapeutic intervention to improve anemia, yet its impact has not been well studied beyond improving hemoglobin values and the potential consequences of iron overload. In these MDS focus groups, some patients voiced concern about the safety related to transfusions; others voiced concern about iron overload. But much more frequently, patients complained that transfusions interfered with their ability to live their lives, in terms of both time and the perceived complicated logistics involved in actually receiving the transfusion. A study of time burden associated with transfusion found the mean total time spent infusing two units of packed red cells to be 4.25 hours.[31] Several focus group participants provided graphic stories of much less efficient transfusion practices.

In an earlier study, MDS patients described enduring a gradual decline in their physical health and functional ability until the hemoglobin level "warranted" transfusion.[32] Researchers assert that the decision to transfuse MDS patients should include patient symptoms[27,29] and QOL data,[18] yet in clinical practice this is infrequently practiced.

Given the lack of curative therapy for most, clinicians have often focused on using "supportive care" methods to treat MDS. Supportive care is commonly defined as providing transfusion, iron chelation, growth factor and antimicrobial support as needed,[20,33] possibly including provision of psychological support.[33] Data from these focus groups suggest that providing "supportive care" may be inadequate, particularly when conveyed with a callous attitude, as depicted by the hematologist who told a patient, "Well, call me if you get a fever above 100 and we'll offer best supportive care."

MDS are a complex, heterogeneous group of diseases. Yet, most patients received little information about MDS in the context of their unique illness trajectory. Informational needs relate not only to the disease process and treatment options but, more importantly, to how the illness and/or treatment will impact a person's ability to live life in the way that he or she is accustomed. In addition to learning about how they will feel as the disease progresses, focus group participants were interested in learning about self-care measures they could utilize to maintain health and functional status. In contrast, providers offered little information about what patients could expect in the future and virtually nothing about steps to maintain health.

Clinicians may have their own concept of the amount, type, and timing of information for patients, which can conflict with the patient's informational needs; this conflict can result in increased anxiety, frustration, and uncertainty for the patient.[21] Moreover, the skill with which professionals present information can be highly valuable. Many patients perceived their hematologist as exhibiting a patronizing attitude toward them. Ageism was commonly encountered, resulting in patients experiencing depression, frustration, or anger. Patients described a lack of exposure to other health professionals, including psychologists and social workers, from whom they could receive assistance in learning how to cope with their illness. Even exposure to the nursing profession was limited to contact when receiving transfusion, infusions, or injections and, thus, was very procedure-oriented with little, if any, time for educationally based interventions. Left without adequate information from their providers, patients sought out information on their own, typically using the Internet. However, without any additional interpretation, obtaining additional information often increased, rather than decreased, the patient's distress.

As evidenced by the focus group participants, people living with MDS often have difficulty coping with uncertainty. Mishel defines this concept as "the inability to determine the meaning of illness-related events,"[34] occurring when one cannot achieve a meaningful interpretation of illness and its treatment. From a patient's perspective, the ambiguity of illness can be highly distressing. In MDS, initial uncertainty can result from the disparity between having a presumably life-threatening illness, with mild, if any, symptoms. Inadequate understanding of the disease process, difficulty deciding what (if any) treatment can or should be employed, and

inability to anticipate the likely disease trajectory can all result in periods of heightened uncertainty.[7,21]

A significant cause of distress is fear of one's disease evolving into acute myeloid leukemia (AML). While this evolution rate is about 30%, the converse rate was not emphasized to these patients; ie, over 70% do not evolve into AML.[27] Even when evolution to AML is not likely, the uncertain nature of the illness trajectory remains a source of distress. The inability or unwillingness of health-care providers to provide anticipatory guidance was common and a source of frustration, anxiety, and depression for patients, as illustrated in the following quote: "My doctor hasn't been able to tell me what kind of symptoms I should expect except fatigue, and that is associated with the anemia. Other than that, he can't tell me anything." Depression also stems from the manner in which patients are told there is (typically) no cure for this disease. Rather than assist patients to accept that, for most individuals, MDS is a chronic illness that one can live *with*, it is much more commonly portrayed as a fatal illness. Coupled with few treatment options (from the patients' perspective), patients are left with the impression that they will die from this disease, with little intervention available to thwart this seemingly inevitable outcome.

Data from these focus groups provide a more comprehensive view of the impact MDS has on a person's life. While previous work has emphasized the impact of MDS on physical well-being (eg, improving anemia or decreasing AML evolution), patients participating in this study described a much broader impact. As one patient eloquently stated, "I think part of the problem is that the focus is so much on the physical improvement, that physicians and nurses alike don't really address the emotional, mental, and spiritual impact."

Providing more comprehensive care, including that rendered by nursing, behavioral medicine/psychology, and social work, is sorely needed and may be a significant factor in improving patients' QOL. Further studies are needed to explore this impact in more detail and to target interventions to better assist patients in coping with this complex, chronic illness.

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