



The Current Therapeutic Landscape and the Patient Experience

**Discussion with IMF
Nurse Leadership Board**

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IMF



**NURSE
LEADERSHIP BOARD**



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Overview

On December 2, 2016, 7 members of the International Myeloma Foundation (IMF) Nurse Leadership Board convened in San Diego, California, in concurrence with the American Society of Hematology (ASH) Annual Meeting, to discuss the following topics as they relate to the current therapeutic landscape and the patient experience:

1. Current therapeutic landscape
2. Patient challenges and education opportunities
3. Unmet needs and best practices for patient care
4. Potential solutions to overcoming barriers and optimizing care

Introduction

Multiple myeloma (MM) is a type of cancer developed by malignant plasma cells in the bone marrow.¹ Abnormal growth of plasma cells and secretion of paraproteins can lead to bone pain and fractures, kidney damage, and immune system dysfunction.^{1,2}

Since 2015, a 6% increase in newly diagnosed MM patients and deaths from the disease occurred.^{3,4} In 2016, approximately 30,300 patients were diagnosed with MM and 12,650 individuals will die from the disease in the U.S. (Figure 1).^{3,4}

While no cure exists, incredible advancements in the diagnosis, treatment, and management of MM have been made

over the past decade.^{5,6} Novel agents have revolutionized the treatment of patients with MM.⁷ For instance, survival rates have improved 92% when comparing MM patients treated from 2001 to 2006 and those treated from 2006 to 2010 (3.8 vs 7.3 years).⁵

The Board's discussions focused on the impact of new therapy options for patient care, as well as benefits and challenges of the new therapeutic landscape and overarching concerns influencing patients' quality of life.

Current Therapeutic Landscape and Patient Care

Overview of the Current Landscape

At diagnosis or relapse, it is optimal for a MM patient's treatment plan to be individualized.⁸ Current classes of drugs for MM treatment include: alkylating agents, chemotherapy, corticosteroids, immunomodulatory agents, proteasome inhibitors, histone deacetylase inhibitors, and monoclonal antibodies.⁹ In the past 14 years, 10 drugs have been approved for treatment of MM and 4 drugs were approved in 2015 (Table 1 and Figure 2).¹⁰⁻¹²

The current treatment landscape provides immeasurable opportunities for improved patient care. Patients are living longer because of the widening landscape. Patients also have more decisional power when determining the best treatment plan for them and their families. Hence, nurses are spending more time with their patients.

The Patient Journey

The current landscape allows for a shared decision-making model of care, whereas the patient, their caregivers, nurses, and physician can mutually decide upon the most suitable treatment option when multiple options are available. For example, many patients and their providers are choosing more outpatient therapy options rather than transplantation. While, outpatient treatment options may positively impact patients' quality of life, they also increase the supportive care and monitoring roles of the nurse.

Financial expenses, physical and psychological challenges are important factors that contribute to long-term treatment and management of MM. As patients live longer, survivorship challenges and symptom management may also influence treatment decisions. For example, many patients are under-insured or uninsured, which results in high copayments for oral medications. Securing oral medications and facilitating support through copayment assistance foundations is often required. During these instances communication with all care team members is vitally important. Clinicians should ask patients about what is an acceptable copayment amount to them, assist with funding support resources, and alert the pharmacy team or prescriber if there are any issues with high copays. Patients that have had MM for a longer period (eg, relapsed-refractory patients) are often overwhelmed and exhausted from the large

quantity of treatment information shared. Treatment information is usually reinforced by a nurse. Trust between the patient and their nurse develops, which then influences their relationship with other care team members. For example, patients are more knowledgeable about their treatment options and nurses are being consulted more to assist with their treatment decision making throughout the disease course at various intervals than in the past.

Most questions from MM patients include the next potential therapy to maintain remission, and the financial burden of treatment options. Receiving information on available treatment options can be helpful to patients but nurses should discern how much information to share.

Palliative care and end-of-life care are important topics of interest for some MM patients. Studies have shown that integrating a palliative care approach, where aggressive control of symptoms is the focus, may allow patients to enjoy better symptom control, which may translate to a better quality and quantity of life. Freely speaking with patients about the benefits of an early palliative care intervention when appropriate, and distinguishing palliative care from end-of-life hospice care is important. Nurses have found these discussions to be difficult when counseling patients but realize their importance, as no cure for MM currently exists. When appropriate, end-of-life care allows patients and caregivers to plan and

include family members in their treatment decisions.

The Role of the Nurse

Vast treatment options can be confusing for both the patient and their providers when determining the most appropriate treatment plan. No clear standard of care exists in terms of sequencing therapies, and personalizing treatment for all patients with MM. Thus, nurses are working longer clinic hours; after-hour discussions with patients have increased and are more frequent; and the need for nursing education resources and support is apparent.

Patients are also asking more questions to more fully understand their treatment options, which contributes to the above challenges. For example, a typical clinic visit has increased from 30 minutes to 1.5 hours. Consequently, infusion appointments may get behind and other patients' treatment schedules delayed.

Nurses spend a great deal of time and energy caring for their patients above their professional obligations. For example, nurses from this advisory board have housed a patient, couched a terminal prognosis using careful language to deter hopelessness and often comfort their patients from diagnosis until end of life. As one nurse expressed, when comforting patients through their treatments, a caregiving role is imitated. A caregiver can be defined as a person who provides physical and/or emotional care to an ill person.¹³ Many nurses spending long clinic

and after-hours time with their patients expressed feelings of exhaustion and burnout. A large body of research suggests the act of caring for chronically ill people can have deleterious effects on a person's health.¹⁴⁻¹⁶ While support for the nurses taking care of MM patients was not discussed, this topic should be explored at future meetings. In the interim, strategies nurses can employ to prevent burnout include: (a) striving to attain a work-life balance (b) developing a network of colleagues who understand the complexities of working with a chronic condition (eg, patients will go through a series of remissions and critical periods of relapse where more support is given) (c) working together with a multidisciplinary team (eg, social workers, nurse practitioners, and other nurses) to provide optimal care for patients so the burden of care is not shouldered by one nurse (d) educating the patients and caregivers on the importance of caregivers engaging in self-care and developing their own support system.

Nursing education has also been impacted by the new landscape. While the need for competent nurses is evident, investment in nursing education has dwindled. For example, prior to the abundance of new therapies, educators were only responsible for teaching a handful of treatment options. Now, due to many different therapy options, it has become increasingly challenging to educate nurses proficiently on the mechanisms of action of these new drugs, side effect management, and

additional nursing considerations. Practical mentoring programs for new nurses may serve as viable tools to augment educational initiatives. In addition to therapeutic trainings, new nurses can also benefit from training on how to collaborate and communicate effectively with other care team members to deliver quality care to their patients.

The Role of Other Care Team Members

All members of the care team for MM patients have unique roles that influence the quality of care of the patient. It is, therefore, important to educate all members of the care team on various options available and to facilitate communication among all care team members. Care team members may include: infusion nurses, primary care and community-based providers, nutritionists, pharmacists, physical therapists, pain management specialists, and social workers. Most hospital systems have electronic medical record systems, which provide the opportunity to share information with care team members, including those from referring centers or outside institutions with a click of the button.

New Therapies on the Horizon

Therapies in this new landscape have improved the maintenance of MM. In addition, the combination of current therapies with transplantation is developing. There has been an increase in clinical trial protocols, also known as

“transplant plus” treatment options, that may influence how MM patients receive care in the future.

Patient Challenges and Potential Solutions

Time

MM patients and caregivers are often challenged with what to ask during their clinic visits. To conserve time, nurses can request that patients email their top concerns (3-5 questions) or the most critical/important questions prior to their clinic visit. A diary or journal of symptoms, nutrition, and blood pressure, for example, could also be suggested to patients to document their journey, and identify reasons for symptoms (eg, fatigue or diarrhea). Providing this type of direction can improve efficiency of clinic visits, minimize the strain of delayed care of other patients, and improve symptom management.

The burden of clinic visits can be stressful to some patients. Longer office appointments, longer wait times, travel to the clinic can be taxing on the patient and caregiver. Nurses should be aware of this issue and consider strategies, such as obtain labs prior to the office visit so results can be discussed. Combining visits with other specialist visits can help, too.

Treatment Decision Making

Depending on the nurse and the institution most nurses communicate with their

patients face-to-face. Electronic tools such as email or patient portals are also used after the clinic visit when additional questions arise. Some patients, depending on length of diagnosis, may become overwhelmed by treatment information shared and seek their trusted nurse's counsel. Nurses should consider providing information in appropriate amounts based on the length of diagnosis, stage of the disease, and whether the treatment needs to be changed promptly. For example, the discussion on-clinical trial or off-clinical trial treatment options will differ based on the need for a prompt change in treatment; and if the patient experiences symptomatic disease progression, versus a slow, asymptomatic, biochemical disease progression with rising M proteins or serum free light chain parameters. While it is important for patients to be included in the treatment decision process, the amount of information shared should be balanced.

Optimizing Care and Quality of Life

It is essential to consider the quality of life of a patient throughout the disease trajectory. Nurses should encourage patients to define their quality of life goals at diagnosis and throughout. Key questions, such as "What is important to you?" and "What are your goals of care?" can assist patients in doing so. The goals of care will be different based on the length of time a patient is being treated (eg, cure at diagnosis for younger patients versus control of the disease with multiple relapses or older patients).

Patients should then have discussions with their care team and family members to ensure their needs are being met. Nurses can also educate patients on supportive care options to maximize mobility, nutrition, symptoms control, and pain management to optimize their quality of life. Working with multidisciplinary team members to weigh the risks and benefits of surgery or radiation, in addition to implementation of a long-term survivorship care plan for MM patients should be considered.

Growing evidence suggests quality of life assessments should be incorporated into the patient's care plan.¹⁷ The Functional Assessment of Cancer Therapy, for example, measures physical, emotional, functional, and social/family well-being and should be conducted on a routine basis.¹⁸ Despite a nurse's demanding schedule, which might prevent a standardized comprehensive assessment, quality of life discussions should be routinely performed.

Financial Barriers to Treatment

Treatment options for MM are often institution-based and financial cost of medications and copays remain a challenge for most patients. Insurance eligibility requirements can be difficult for patients receiving care at community versus academic institutions. The decision to sequence therapies or give a patient an intravenous rather than oral therapy can be influenced by finances. Supportive care medications may also add to the financial

burden as side effects from treatment surface. To minimize financial burdens for patients and their families, nurses and other care team members can: serve as advocates, provide information on financial assistance programs, and serve as mediators between the insurance providers and their patients.

Closing Statements

The role of the nurse in this new therapeutic landscape has great promise for development of innovative care models for MM patients. Patients now have more options and more questions. Patients look to their nurses for support, encouragement, and comfort. Since the hours for caring for patients and the nursing roles have changed, nurses are encouraged to collaborate with other care team members and be a part of the shared decision-making

process. As the well-being of nurses affects the quality of care the patient receives,¹⁹ collaboration with other team members could optimize care for MM patients, and reduce the risk of oncology nurse burnout.

It is important for nurses to continue to educate patients and other healthcare providers about the collection of treatment options now available, and the impact on patient care. Each nurse brings experiences and insights to their institution that can be shared and developed into best practices to improve the care offered to patients with MM. As innovative care models are developed, nurses should find ways of disseminating information through mentoring-education programs and present information using various communication platforms (eg, blogs, local and national conferences).

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Figure 1 Multiple Myeloma Patients in the U.S. (2015 to 2016)

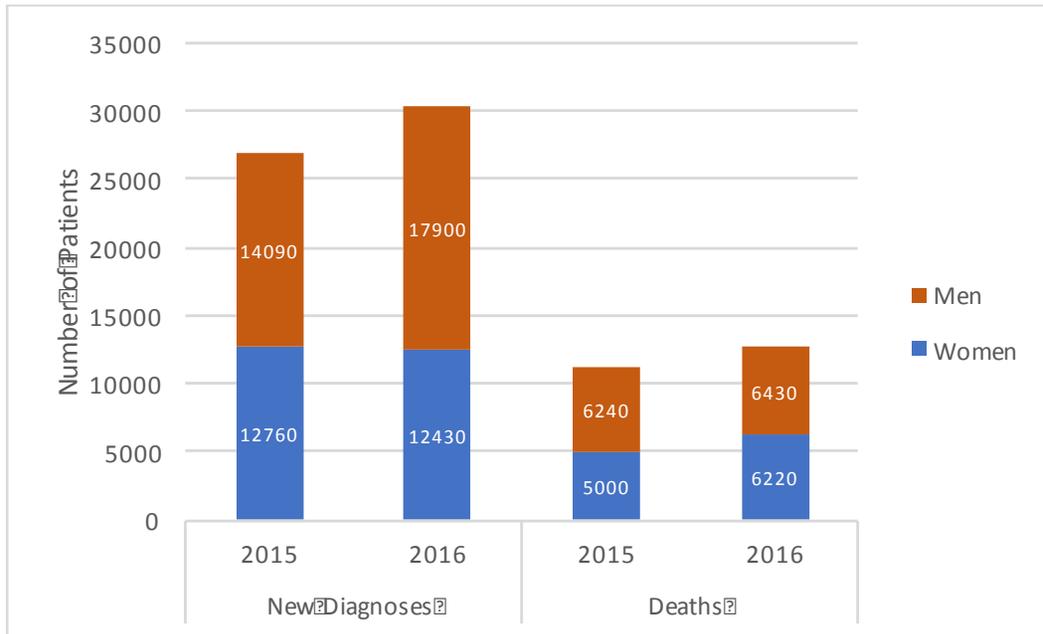


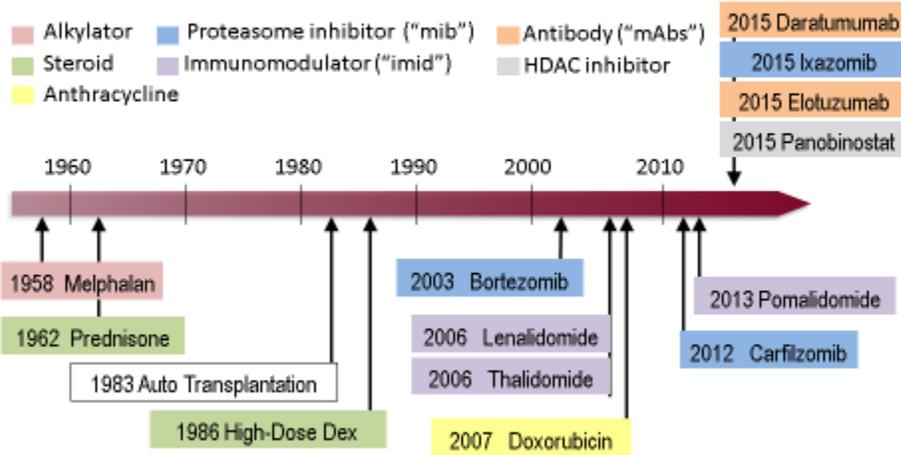
Table 1 Drug Treatments for Multiple Myeloma Patients (Approved since 2000)

Year	Generic Name	Brand Name	Indication
2015	Daratumumab	Darzalex	Relapsed MM after at least 3 prior treatments
	Elotuzumab	Empliciti	Relapsed MM after 1 to 3 prior treatments
	Panobinostat	Farydak	Relapsed MM after at least 2 prior treatments
	Ixazomib	Ninlaro	Relapsed and refractory MM after at least 1 prior treatment
2013	Pomalidomide	Pomalyst	Relapsed and refractory MM after at least 2 prior treatments
2012	Carfilzomib	Kyprolis	Relapsed and refractory MM after at least 2 prior treatments
2008	Plerixafor injection	Mozobil	Hematopoietic stem cell mobilizer
2006	Thalidomide	Thalomid	Newly diagnosed MM
2005	Lenalidomide	Revlimid	Relapsed MM after at least 1 prior treatment
2003	Bortezomib	Velcade	Relapsed MM after at least 2 prior treatments

Figure 2 Treatment Options Timeline for Multiple Myeloma



2015 was an Amazing Year in Expanding Treatment Options for Multiple Myeloma



Auto = Autologous; Dex= Dexamethasone