



The Oncology Nurse-APN/PA®

The Official Publication for the Hem/Onc Nurse & Advanced Practitioner

The Pivotal Role of Oncology Nurses in the Care of Patients with Multiple Myeloma



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The Pivotal Role of Oncology Nurses in the Care of Patients With Multiple Myeloma

The past decade has witnessed dramatic progress in the treatment of multiple myeloma (MM), which has resulted in unprecedented improvements in survival outcomes. According to the Surveillance, Epidemiology, and End Results database analysis, the 5-year survival rate of patients with MM has increased from 25% in 1975 to 47% in 2010.¹ This achievement is largely attributed to the advent of a new generation of potent MM therapies.²

Therefore, patients with MM are living longer and are dealing with a different set of challenges than they previously encountered; it is imperative that healthcare providers gain understanding of these issues to deliver optimal patient care.

A roundtable discussion consisting of patients with MM was held in Boston, MA, on July 14, 2015, to hear the patients' unique voices and gain insights into the challenges and unmet needs in the care of patients with MM. This article presents the proceedings of the meeting, highlighting patients' perspectives on barriers to care and variation in care, resulting in unmet needs for this patient population.

This synthesis of the patient voice provides invaluable and actionable insights into the challenges that patients with MM face.

The participating patients were Jack Aiello (San Jose, California), Cheryl Boyce (Columbus, Ohio), Yelak Biru (Dallas, Texas), Cynthia Chmielewski (Lawrenceville, New Jersey), and Gary Petersen (Jacksonville, Florida), all of whom expressed their perspectives afforded by their individual struggles with the disease, as well as their interactions with their care team and their communities of patients with MM.

Oncology Nurses in Patient Care

Considering that nurses are the healthcare professionals with the most interpersonal contact with the patient, they play many vital roles in the care of their patients, including that of caregiver, communicator, educator, and advocate. Nurses also serve as a conduit for dissemination and coordination of information between patients and the healthcare team. Therefore, from their position at the

frontline of treating patients with MM, nurses must be understanding and empathetic to the unique needs, challenges, and viewpoints of patients throughout the disease continuum, from diagnosis through survivorship.

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The roundtable explored important aspects of the care of patients with MM, including issues that patients consider in deciding between current treatment options, their interaction with the oncology care team, identifying barriers to oral medication adherence, how they managed treatment-related side effects, and identification of unmet gaps in patient care. This synthesis of the patient voice provides invaluable and actionable insights into the challenges that patients with MM face, so that nurses may direct their efforts to improving the care of patients with MM.

Treatment Advancements and Patient Empowerment

The group concurred that the exponential increase in innovative treatment options for patients with MM is a major development, which was a great source of hope for the patients. The group considered the acceleration of Internet technology as another significant development of the past decade, which has positively contributed to the development of online patient communities and support groups. Such online communities and educational portals are thought to have provided exceptional avenues for patients to educate themselves on the latest advances in MM treatment.

The roundtable group credited these advances as the source for the emergence of an "empowered patient," who is well-informed about the available treatment options for MM and, therefore, is more involved in his or her treatment, while also expecting delivery of optimal patient care.

As a corollary to the treatment advances and patient empowerment, the group indicated a corresponding increase in the patient's uncertainty and anxiety in terms of which treatment option is best for the individual patient. The group conveyed that being actively involved in the decision-making process by considering the benefits and trade-offs of each treatment, and having a better understanding of their overall treatment plan, may curb their fears and uncertainties.

Developing a Treatment Plan

To outline a potential treatment plan, the patients suggested using an integrated schema or framework that is broadly classified by the different treatment phases (eg, induction, transplant, maintenance), with potential treatment options included for each phase of the disease. The schema must be individualized to the patient, considering factors such as the patient's previous response to therapy, disease aggressiveness, comorbidities, and genetic profile.

Participants indicated that they recognized the inevitability of disease relapse in MM, and that they preferred to be aware upfront of the treatment plan the oncologist is leaning toward, so that they could be better prepared for the inevitable.

From a patient's viewpoint, the group outlined the key factors that must be considered when developing an optimal treatment plan, namely, robustness of efficacy and safety data supporting the treatment decision, alignment with clinical practice guidelines, and effect on the patient's quality of life.

As a corollary to the treatment advances and patient empowerment, the group indicated a corresponding increase in the patient's uncertainty and anxiety in terms of which treatment option is best for the individual patient.

This discussion highlights the unmet needs of patients with MM for healthcare providers to better engage with this patient population and involve patients with MM in designing their treatment plan and minimizing the barriers to care.

Care Variation a Major Concern

The group acknowledged that patients are not medical experts and therefore must learn to defer to the judgment of their care providers and healthcare professionals.

However, the patient participants voiced their perceptions that a major area of concern for them was the practice variations between care settings, such as large academic institutions and community oncology centers. The group noted that healthcare providers practicing in the community setting often show substantial knowledge gaps in the management of patients with MM, which applied to oncologists and nurse professionals.

The patient participants voiced their perceptions that a major area of concern for them was the practice variations between care settings, such as large academic institutions and community oncology centers.

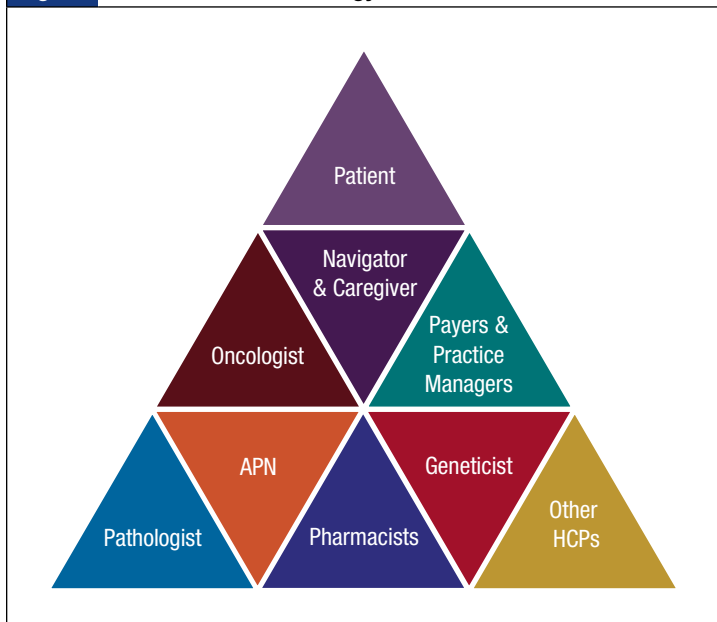
Compounding this lack of knowledge was the fact that patients with MM comprise a small fraction of the patients that make up the practice of a community hematology/oncology center. These factors were thought to contribute to practice gaps based on the site of care, with some physicians showing a good grasp of MM treatment, whereas others are unable to design an optimal treatment plan.

In the words of one participant, "There are some doctors who just know what to do, and it's practice. Practice makes perfect. If you only see a few patients, and are confronted with everything, you just don't have the skills to do it correctly."

The group reported wide variation in treatment practice even among MM specialists, with some specialists adopting a conservative treatment approach and others favoring more aggressive treatments. This can also be a cause for confusion and uncertainty for patients. As one participant said, "Should I have the kitchen sink thrown at me, or should I go for the minimalist? We don't know, and that's what's confusing and frustrating. Then you sometimes second-guess yourself."

The participants pointed to practice variations among MM specialists even in the way physical examinations are conducted. "I see 2 myeloma specialists, and depending on which doctor I go to, I get treated differently. In one of the specialist groups, they don't just ask me. They actually do. They listen to my heart. They listen to my bowel sounds. They measure my height. They don't just go through the checklist. They check my feet and see if I have edema. The other group, they just ask, 'Any swelling? How do you feel?' Even between specialists, your physical exam is different."

Notably, the group indicated that there was considerable disparity in the knowledge base of nurses who are practicing in large institutions and those practicing in

Figure Structure of an Oncology Care Team

community oncology centers. This was a source of considerable concern and frustration for patients, given their greater interaction with nurses than with other health-care professionals.

As one of the participants stated, “When you’re talking about small community practice, I really don’t believe that the nurses that I deal with understand multiple myeloma, understand the side effects of multiple myeloma....I almost teach them, instead of them teaching me.”

The group also indicated that nurses are not always well-informed about drug infusion procedures or the side effect profiles of common MM drugs.

These patient insights underscore the need for targeted and continuing education of nurses, particularly those practicing in community oncology settings.

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Barriers to Clinical Trial Enrollment

Although clinical trial enrollment is a valid treatment option in certain settings,³ the group conveyed that it is a concept that is not well-received by patients. Several barriers for this reluctance to enroll in clinical trials were cited, including patients’ lack of awareness of relevant

trials, inconvenience of traveling to a trial center, or “feeling like a guinea pig.”

In addition, one participant shared, “Many patients go to community doctors who don’t have those trials available, and even if the doctor knows about them, may not want to lose a patient.”

The participants urged pharmaceutical companies and clinicians to increase patients’ awareness about clinical trials, particularly regarding their design and execution. It was suggested further that discussions about potential clinical trial enrollment must be initiated during disease remission, so that patients may get “more acclimated to the idea of participating in clinical trials.” One patient said it is “a horrible time to introduce [it] when you’re eligible for one.”

The care team should, at a minimum, consist of the patient, medical oncologist, navigator, primary care physician, advanced practice nurse, nurse, pathologist, pharmacist, and payers or practice managers.

Other reasons mentioned for pushback on clinical trial participation included stringent clinical trial exclusion criteria, and the fear of being randomized to receive the inferior treatment. Moreover, the group suggested reinforcement of the message that commercial insurance and Medicare often cover the treatments used in clinical trials.

The Oncology Care Team

The group defined the key players of the oncology care team from the patient perspective, and whom they considered to be the most critical team member. According to the participants, the care team should, at a minimum, consist of the patient, medical oncologist, navigator, primary care physician (PCP), advanced practice nurse, nurse, pathologist, pharmacist, and payers or practice managers (**Figure**).

According to the patients’ suggestions, other health-care providers that may be included in the care team are health plan case managers, societies and support groups, practice administrative staff besides the practice manager, social workers, supportive care team, mental health specialists, complementary and alternative medicine (integrative medicine) specialists, nutritionists, and spiritual support personnel.

Because of the distinctive roles played by community oncologists and oncology specialists during the MM disease continuum, it was put forward that both types of on-

cologists be included as separate entities on the care team.

The group shared that the patients' need for each of the team members evolved during the disease continuum, depending on their need, stage of their disease, and geographical location. The group concurred that the medical oncologist is regarded as the primary member of the care team.

However, the type of oncologist that patients interacted with changed at different time points of the disease course. "A community-based oncologist" is appropriate during stable disease and can provide "a relationship, maybe a bedside manner, a connection." Whereas during disease relapse, "a more research-based oncologist that is looking further" is needed.

The group pointed out that although they preferred to approach the oncologist for critical conversations, they may be willing to talk to a well-informed and knowledgeable nurse practitioner instead.

It was suggested that a PCP also plays an important role in patient care during the disease continuum, and the PCP is the most critical person at the beginning of the cancer journey, because of his or her involvement in the disease diagnosis. Furthermore, the PCP care continues to be vital in the overall healthcare of the patient, by providing supportive care and treating other comorbid conditions.

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Barriers to Care Coordination

The group emphasized the lack of care coordination among the different stakeholders in the care team, which leads to fragmented care and a consequent lack of empathy for the struggles of the patient.

In one participant's words, "I felt like it was probably the most disjointed I had ever seen the system in terms of how to get from place to place. People would set up appointments across town and all kind of stuff. I feel like when you get cancer, there's almost an insensitivity of the people who provide the treatment, in terms of your life."

Another participant elaborated on the lack of care coordination as including "even information flowing from the oncologist to the internist. If I have somebody on 2 systems, it really is up to me to provide that bridge

of information between those 2 different organizations."

These highlights provide insights into deficits in patient care that are actionable; it was suggested that a single point of contact, such as a healthcare assistant or a navigator coordinating care would be of great benefit in maintaining continuity of care for patients.

An example of survivorship planning with profound life course implications is the potential for fertility issues with stem-cell transplantation.

Supportive Care and Survivorship Care Plans

The group noted that the majority of cancer care teams lacked a dedicated supportive care component. However, the participants emphasized the critical role played by this team in side effect management and prevention. As stated by one participant, "They go through, and they'll train you. If you [are running a] temperature, [they say], 'Don't wait until your temperature is 102. When it's 100.5, this is what you do. If it maintains, then you go take an antibiotic, and you always have one available.'"

To address this unmet need, it is conceivable that this role may be fulfilled by a nurse professional in the absence of a dedicated supportive care team.

The group also mentioned the lack of care plans to address survivorship issues, which are now clinically relevant given that patients with MM are living longer. An example of survivorship planning with profound life course implications is the potential for fertility issues with stem-cell transplantation.

The group envisioned a survivorship care plan to be a complete document or "blueprint" that contained information on the patient diagnosis, treating physicians, treatment history including pathology, treatment plan, reported side effects and their management, and other screenings—all of which could be accessed electronically and by all stakeholders.

Considering that oncology nurses play an important role in the provision of survivorship care, the onus of having these discussions may fall on them.

For a patient, MM support communities are indispensable in providing MM education and overall patient support. Unfortunately, patients encountered practice variations in terms of oncology practices recognizing the immense benefit that patients derive from this resource. Although the academic oncology teams provide patients with avenues to interact with support groups, their community counterparts do not. Based on this patient feedback, oncology nurses must make an effort to provide referrals to community or online support groups.

Gaps in Patient Education on Side Effect Management

A session was dedicated to the discussion of practice gaps and other challenges patients with MM face regarding management of treatment-related side effects. It was suggested that some patients may show reluctance in reporting side effects, because it may lead to discontinuation of an active drug.

In this context, it is critical that it is communicated to the patient that most side effects can be managed and may not require treatment discontinuation. Moreover, it is conceivable that patients using oral therapy, because of their reduced interaction with their practices, may not recognize and readily communicate side effects to the care team.

According to the participants, nurses should educate patients on anticipated side effects before treatment initiation, and be proactive in specifically probing for side effects during the course of therapy.

According to the participants, nurses should educate patients on anticipated side effects before treatment initiation, and be proactive in specifically probing for side effects during the course of therapy. It was also recommended that educational materials be provided to patients on drug-specific side effects, and to enumerate the major effects, preferably using an acronym for easy remembrance.

The group conveyed that it is often difficult for patients to determine whether side effects are treatment- or disease-related, further reinforcing the importance of having open communications with the MM care team to distinguish between the specific types of side effects.

Moreover, the group emphasized the need for documenting a baseline side effect profile for each patient, so that “subsequent testing [may] be done in relation to that baseline.” As one participant explained, “For example, if you know what your baseline pain is, then you tell your physician when it’s worse than usual.”

Of concern, the participants reported that community practices provided minimal side effect resolution or education and trivialized the side effects they were experiencing. One participant explained, “Teach them about side effects, how to dose-reduce when necessary, not follow just the standard protocol, but ask questions. Not one nurse has ever asked me, ‘How’s your neuropathy?’ or given me a test to see if I could hold things. Unless I bring it up, I’m not asked.”

Echoing these sentiments, another participant stated,

“If you look okay, and your numbers are doing okay, they don’t even want to entertain some of the side effects that you may be experiencing. Everything that I was saying was being dismissed, because my blood counts looked good, my platelets were okay.”

One participant went on to elaborate about how her complaints about fatigue were not addressed. “No one bothered to tell me that maybe if I took my medication at night and used it as a sleeping pill, I might have less fatigue. I learned that in the support group. I didn’t join a support group until maybe 4 or 5 months after my diagnosis.”

Moreover, the group mentioned that some physicians prescribe antiemetic and antiviral agents prophylactically, whereas others do not.

The group identified the following 4 categories of MM treatment-related side effects that they are most concerned with:

- Cognitive (chemo brain)
- Gastrointestinal
- Fatigue
- Neuropathy.

It was suggested that “there should be a checklist that they’re asking for patients with myeloma, depending on what treatment they’re on.”

Pain was also mentioned as a ubiquitous side effect that patients with MM contend with but are not adequately treated for. It was noted that different patients have different pain thresholds, and that it can be difficult to assess pain using self-reporting methods, highlighting the need for routine pain assessments for all patients with MM using standard assessment tools.

Of note, it was suggested that each patient has their individual outlook on the risks and benefits of a specific treatment, and it is imperative that the care team determines the patient’s standpoint before designing the treatment plan.

Pain was also mentioned as a ubiquitous side effect that patients with MM contend with but are not adequately treated for.

Overall, the patient feedback underlines the presence of significant practice gaps in terms of MM treatment-related side effect education and management, indicating an urgent need for improving patient care in this area.

Medication Adherence

Oral therapy is an important trend in the practice of oncology, with 4 new-generation oral drugs currently approved for the treatment of patients with MM.⁴ In ad-

dition to oral therapy being more convenient, easier, and faster to administer, the participants considered oral treatment to be liberating, restore their dignity, and change their perception of their sickness.

However, a shift in burden with oral therapy is well-recognized, with the patient assuming the burden of medication adherence.⁵ Unfortunately, many patients are not adherent to their treatment and often failed to take the drug as prescribed.⁵ This lack of adherence to prescribed therapy is known to be a major contributor to suboptimal drug treatment and poor outcomes.⁶

Several participants liked the idea of in-office dispensing, especially if a nurse or a pharmacist can provide on-site education.

Several patient barriers to medication adherence were reported. Foremost, the group stated that patients perceive oral drugs as being more expensive. Out-of-pocket expense was mentioned as a major issue for patients, with some attempting to “stretch out” prescription fills by underdosing or missing doses.

One participant explained that many patients may not be covered by oral parity laws in relevant states, and for those who are, the out-of-pocket costs may still be higher than what some patients can afford to pay for drugs covered under the pharmacy benefit. Although patient assistance programs offered by manufacturers and nonprofit foundations are available for such patients, it was noted that many practices and patients are unaware of the existence of such financial resources and, consequently, do not avail of these opportunities.

A practice-related barrier cited was that many practices consider that it is time-consuming and resource-intensive for them to help patients determine financial assistance options, so these options are not offered to patients. For these same reasons, and because they want to initiate treatment quickly, they opt to initiate an intravenous treatment instead of oral therapy.

The group also revealed that several other practical and patient-related barriers to medication adherence—including side effects, cognitive issues such as forgetting to take oral medication, and delays in obtaining insurance approvals—can interrupt therapy. It was noted that home delivery can be a challenge, because a signature is often required. In this context, several participants liked the idea of in-office dispensing, especially if a nurse or a pharmacist can provide on-site education.

Some patients find coordinating refills with the blood test required for REMS compliance to be challenging,

and may result in suboptimal adherence. It was noted that dosing schedules may also impact adherence, where once-daily dosing may be easier to adhere to compared with once-weekly dosing, because it is easier to remember. The group stressed that it was important to educate patients about drug–drug interactions and drug–food interactions, particularly in relation to oral drugs.

The participants also mentioned the need for product-specific checklists to help them monitor side effects and stay on track with their oral medications. In particular, the group was receptive to the development of tools to help track side effects and send medication reminders. One participant explained, “The ability to have, or a means to have to record your side effects over a period of time, that actually change, and be able to present that in a meaningful way to your doctor when you are visiting him on a monthly basis for your lab results or something like that, I think would be very helpful.” The group recommended introducing tools and resources with appropriate educational support.

Conclusions and Recommendations

Patients offer a unique perspective regarding the key challenges and unmet needs that they face during the course of their treatment for MM. Challenges and shortcomings identified by patients include practice variability among MM specialists and community oncologists, lack of knowledge regarding appropriate side effect education and management, limited baseline health testing, lack of coordination among the different stakeholders in the care team, and the limited role of the supportive care team in patient management and survivorship care planning.

The participants also mentioned the need for product-specific checklists to help them monitor side effects and stay on track with their oral medications. In particular, the group was receptive to the development of tools to help track side effects and send medication reminders.

The discussions also highlighted patient recommendations to remedy these deficits, many of which are of particular relevance to a nurse professional. Recognizing the knowledge gaps between academic centers and community providers, the group recommended the development of peer-to-peer educational programs targeting the community oncology provider and nursing professionals.

In view of feedback that community practices provided

minimal side effect education, trivialized the side effects patients experienced, and did not adequately address side effects, healthcare providers, including nurses, must focus their efforts to mitigate these gaps in management. They must proactively set patient expectations about side effects, possible dose adjustment, and potential for relapse, before treatment initiation. They must also help patients discern between disease- and treatment-emergent side effects, so that they may be appropriately managed.

The group also recommended the development of education-level appropriate product- or regimen-specific checklists to meet the ongoing need for improved side effect education and management. For patients using oral therapy, regular medication adherence monitoring, as well as proactive assessment and resolution of barriers to medication adherence, was recommended. Given the long-term survival of patients with MM, supportive and survivorship care issues are a clinical reality that nurses must engage in.

Healthcare providers, including nurses, must focus their efforts to mitigate these gaps in management. They must proactively set patient expectations about side effects, possible dose adjustment, and potential for relapse, before treatment initiation.

Importantly, it was learned that nurses must recognize that each patient's needs are different, and that they must individualize the delivery of care to their unique needs.

Given that MM care is often fragmented, with patients with MM frequently transitioning between community oncologists and specialists, as well as being under

the care of PCPs for maintenance of overall health, the participants indicated that a single point of contact to help guide them through the disease continuum would be most beneficial. It was suggested that nurse navigators may play a critical role in such care coordination, and a recommendation was made for the institution of navigator initiatives in conjunction with the development of educational tools and resources directed specifically for navigators.

The participants indicated that a single point of contact to help guide them through the disease continuum would be most beneficial. It was suggested that nurse navigators may play a critical role in such care coordination.

Taken together, to accommodate patient needs and the evolving healthcare delivery landscape, the role of the oncology nurse must focus on several aspects of patient care, including patient assessment, patient education, coordination of care, symptom management, supportive care, and survivorship care.

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