

Enhancing the patient–healthcare professional relationship in multiple myeloma

This whitepaper highlights the important role that information and education play in a complex disease such as multiple myeloma in shaping the relationship between the patient and healthcare professional



Introduction

A strong relationship between patients and healthcare professionals (HCPs) plays a key role in achieving quality healthcare and positive health outcomes, with good communication at the core of this dynamic.¹⁻³

In a complex disease such as multiple myeloma (MM), effective communication and collaboration between patients and HCPs are critical. HCPs are faced with an unpredictable disease in terms of biological and clinical characteristics, treatment response and clinical outcomes, which can make diagnosis, treatment and management of this condition challenging.⁴ On the other hand, patients with MM often have to cope with months or even years of uncertainty before a diagnosis is reached, come to terms with and learn about a cancer they may not have heard of, and live with an incrementally progressive disease that is associated with a high physical and psychosocial burden.^{5,6}

Although HCPs have a responsibility to encourage communication and provide education for patients, it is only effective when it is based on two-way, open and honest dialogue that enables meaningful exchange of relevant information from both parties. There is an opportunity to support patients with MM and HCPs by offering tools and resources to facilitate good communication and enhance the relationship between them. This support can help reduce communication barriers and create a partnership that consists of shared perceptions regarding expectations, treatment goals and long-term outcomes, leading to greater patient and HCP satisfaction

About multiple myeloma

MM is characterized by the clonal expansion of malignant plasma cells within the bone marrow, resulting in bone destruction, anaemia, immunodeficiency with recurrent infections, kidney failure and hypercalcaemia.⁷

MM is the second most common haematological malignancy, with approximately 160,000 people diagnosed globally per year and is the cause of some 106,000 deaths per year worldwide.⁸ The estimated annual incidence in the United States and European Union is 6.5 and 5.7 per 100,000 population, respectively.^{6,9} Since the median age of patients at diagnosis is approximately 70 years, MM is mainly a disease of older people and incidence rises steeply with increasing age: only 37% of patients are younger than 65 years of age and less than 0.3% are younger than 30 years.^{10,11} The incidence of MM is expected to rise as the global population ages.¹²

A heterogeneous disease

MM is highly heterogeneous; no two patients have the same experience in terms of clinical features and disease outcomes. This heterogeneity is largely due to the underlying pathobiology of MM, in which multiple genomic events lead to tumour development and progression (see Box 1).

Clinically, MM can vary from asymptomatic forms to overt malignant disease with severe end-organ damage and high symptom burden. While some patients have extensive bone disease as the leading clinical problem at presentation, other patients may be more affected

by cytopenias or kidney impairment.¹³ In addition, some patients may have less common manifestations such as peripheral neuropathy, hyperviscosity or skin manifestations. As a result of these burdensome symptoms, patients experience a significant impact on their quality of life.

Survival outcomes also reflect disease heterogeneity in MM. With the same treatment, some patients can be progression-free for more than 15 years, whereas others may have a median survival of less than 2 years.¹³

BOX 1 / Pathobiology of MM: basis of heterogeneity

Under healthy conditions, antigen-specific immunoglobulin production involves gene-editing processes, such as class switch recombination and somatic hypermutation, that allow for the diversity of antibodies necessary to fight pathogens. However, these processes are error prone and can lead to oncogenic proliferation and the production of clonal plasma cells, resulting in the development of MM.¹⁴ In half of patients, the clone is initiated by one of several chromosomal translocations, and in the other half by acquiring a hyperdiploid karyotype.^{13,14}

Additional mutations, whether secondary translocations, point mutations or chromosomal copy number abnormalities, drive clonal evolution, giving rise to a heterogeneous population of myeloma cells in the bone marrow.¹⁴ By the time of diagnosis, patients can harbour between three and seven different subclones, each potentially associated with different clinical behaviour and sensitivity to treatment.^{15,16} Further genomic events continue throughout the disease course, increasing clonal diversity, driving disease progression and treatment resistance.

Both inter-patient and intra-tumour heterogeneity are therefore major causes underlying the heterogeneous nature of MM.

Treatment of multiple myeloma

In the past two decades, clinical outcomes and survival in patients with MM have improved dramatically as therapeutic options have increased and supportive care has evolved.^{17,18} Six active drug classes are now approved for the treatment of MM (Table 1).^{19,20} Next-generation, novel drug classes and drug combinations in clinical trials provide further options for patients.

Treatment choice in MM depends on patients' age, disease complications, existing co-morbidities and whether they are eligible for autologous haematopoietic stem cell transplantation. Treatment typically involves repeated cycles of two to four drug combinations with a proteasome inhibitor, immunomodulatory drug, monoclonal antibody, alkylating agent or steroid, of fixed duration or as continuous therapy.^{19,20}

Despite improvements, not all patients benefit from the newer therapies. Survival remains poor for patients defined as high risk, especially those carrying specific genetic abnormalities (eg del[17p], t[4;14], del[1p32], 1q gains).²¹ Virtually all patients will relapse and/or become refractory to treatment, with most requiring multiple lines of therapy. Treatment becomes more challenging with each

subsequent line of therapy as resistant malignant clones are enriched after each relapse.¹⁶ Furthermore, cumulative toxicity increases while bone marrow function decreases with each line of therapy.²² Consequently, optimal treatment sequencing and changing treatment goals are among the most difficult challenges HCPs face in daily clinical practice.

Table 1. Drug classes approved for the treatment of MM

Drug class	Anti-MM activity
Proteasome inhibitors	Multiple biological effects, including accumulation of cyclin- or cyclin-dependant kinase inhibitors and tumour suppressor proteins; inhibition of the clearance of misfolded proteins; blockade of the NF-κB transcription factor pathway
Immunomodulatory drugs	Exert immune regulatory function and interfere with tumour microenvironment interactions
Histone deacetylase inhibitors	Inhibit genetic inactivation of p53 and the blockade of the unfolded protein response
Monoclonal antibodies	Target specific antigens present in MM cells to activate the immune system
Nuclear export inhibitors	Block exportin1 and prevent nuclear transport, causing cell cycle arrest and cell death by apoptosis
Alkylating agents	Interfere with DNA replication by crosslinking DNA strands

NF, nuclear factor

The importance of a strong patient–healthcare professional relationship

The needs of patients with MM are numerous and complex. They broadly represent a group of older patients dealing with a chronic yet life-threatening disease and complex treatment pathways. Many experience a high disease- and treatment-related symptom burden that compromises health-related quality of life even during periods of remission.²³ As a result, patients with MM require multiple levels of support from HCPs to help them adjust to living with a debilitating disease that has high levels of uncertainty around treatment success and disease progression.^{24,25}

Most patients with MM are under the care of a dedicated expert multidisciplinary team led by haematologist-oncologists and specialist nurses that may also include orthopaedic specialists, radiologists, nephrologists, psychologists, social workers, dieticians and palliative specialists. Because of its relapsing and remitting nature, management of patients with MM involves life-long follow-up care that is more typical of a chronic disease than cancer. HCPs should therefore use every opportunity to develop a strong and effective relationship with their patients based on mutual respect and trust, built from open and transparent dialogue.²⁶ Patients should feel informed, in control and empowered to engage in the decision-making processes related to their treatment and care.

Good communication is critical from the outset. Most patients have never heard of MM before, and on receiving a diagnosis, face many unknowns regarding the physical, emotional, social and financial impact of the disease. At this point, the information needs of patients and their families should be met to help them come to terms with the diagnosis and understand the impact MM will have on their lives, and what treatment options are available. HCPs should gauge what level of information each patient is comfortable with, tailor it accordingly and deliver it with respect, honesty and empathy. For example, some patients with MM may want to know more about their future prognosis, the cause and course of disease as well as the long-term effects of treatment, whereas others might not. Some patients are also interested in hearing about other patients' experiences.²⁷ Other key periods when information and support may be required are around times of relapse.²⁸

Common challenges patients face when seeking information include not knowing which sources are trustworthy and difficulty in finding what they are looking for. As part of a structured approach to care, HCPs need to be able to provide or signpost patients to resources that are up-to-date, accurate, reliable and best suit their needs.

How we can help

- Patient information landscape mapping to explore what is available, identify gaps and generate resources to meet patient needs
- Effective educational resources (digital and print) for patients to support and supplement the verbal information given during consultations about MM, its treatments and their side-effects
- Online communities, virtual or face-to-face support groups and events to help facilitate patient networking
- Resources (digital and print) that capture patients' and caregivers' lived experiences of different aspects/stages of MM for patient and HCP audiences

Through effective communication, the holistic needs of patients can also be met. Patients often want to know how to keep as well as possible and may have practical day-to-day concerns such as the ability to continue to work and participate in routine exercise, dietary changes, etc.²⁹ Apart from the physical morbidity of living with MM, patients may experience emotional fluctuations during the relapsing-remitting phases.²⁸ They may also find it difficult to come to terms with the incurable nature of the disease and have anxieties about loss of income due to the significant time investment on treatment. In particular, the haematologist-oncologist and/or the specialist nurse should discuss the emotional impact of MM and its treatments early following diagnosis to avoid it being a source of ongoing stress for patients. Where appropriate, referrals should be made to relevant support services such as psychologists and social services. Patients should be encouraged to report any side effects of treatment, including often overlooked issues such as changes in libido and the effect on cognitive ability or mood, so that they can be mitigated as

soon as possible. HCPs should also be aware of and be prepared to address the emotional toll of the disease with their patients, particularly during times of relapse.²⁸

How we can help

- Resources that cover more practical and emotional aspects of MM to help patients live well with the disease
- Learning resources for HCPs to improve communication skills and information giving; eg providing emotional support, implications of high-risk disease, breaking bad news

A good relationship with their HCP will help patients feel comfortable about discussing their treatment goals, needs and preferences and what trade-offs (eg side effects, route of administration) they are prepared to take when considering treatment options. When planning treatment, HCPs should help patients understand the expectations of each therapy, the associated side effects and the possible impact of the therapy on quality of life. By being informed about treatment options and outcomes in terms of risks and benefits, patients can be involved in shared decision-making. They are also more likely to adhere to and complete their treatment, and report back on any problems they encounter during this period,³⁰ although patients do generally adhere to anti-MM treatment (see Box 2).

How we can help

- Shared-decision tools that allows patients to consider potential treatments and their impacts, and align their preferences prior to discussions with HCPs

BOX 2 / Treatment adherence in MM

Several approved drugs for MM are orally administered and the potential issue of treatment adherence is of great importance. While evidence suggests that adherence is high, especially to immunomodulatory drugs,³¹ it may be influenced by patient health status and quality of life. Indeed, patients with MM who have a low level of activity impairment and preserved quality of life demonstrate greater adherence to oral treatment than those with higher physical burden and reduced quality of life.³²

Benefits of a good patient–HCP relationship

Patients

- Feel empowered to make informed decisions about their treatment and care
- Take an active role in their treatment and self-management
- Have realistic expectations of treatment outcomes
- Adhere to treatment
- Feel satisfied with their treatment and care
- Show improved health outcomes and quality of life

Educational support for healthcare professionals

HCPs

- Are able to conduct engaging and time-efficient consultations
- Have reported enhanced morale, reduced work-related stress and greater job satisfaction

For HCPs working in the field of MM, it is, without doubt, an exciting time. New clinical and real-world data are emerging, and new drugs are being approved at a remarkable rate. However, this comes at a price: within their busy schedules, HCPs must keep up to date with the latest developments and the resulting implications for clinical practice and their patients.

For example, treatment decisions are becoming more complex in MM as the number of available options increases. While decisions at first-line are relatively straight-forward, decisions at relapse are more challenging in terms of which drug(s) to use, when to use them and in what sequence. No simple treatment algorithm exists to guide the HCP and the choice can be affected by patient-, treatment- and disease-related factors as well as patient preferences.^{33,34}

Furthermore, with successive lines of therapy, decisions may also be influenced by treatment accessibility/affordability, toxicity burden, impact on quality of life, the emergence of therapeutic resistance, and what remaining treatment options there are or can be reused.

To preserve and strengthen the relationship with their patients, HCPs must be confident and competent in communicating the options available and the decisions they make. To do so, they must keep abreast of the available data, evolving guidance and latest best practices and consider how these impact individual patients. HCPs therefore need to have the right education, in the right format, at the right time to help make decisions in which they feel confident.

For the time-pressed HCP, high-quality easily digestible resources of clinical value can help make their tasks easier. Increasingly, HCPs are turning to digital information and remote e-learning, welcoming the accessibility, flexibility and convenience these platforms offer over traditional face-to-face opportunities. Several MM-specific online medical education resources exist and this trend towards the digital format is likely to continue, expedited by the effects of the COVID-19 pandemic. Of note, COVID-19 has provided the opportunity to rethink the scientific meeting and, in future, virtual conferences may even become the norm.

How we can help

- Qualitative analysis of existing educational resources and in-depth research to identify the educational needs and wants of HCPs
- Digital engagement platform to provide HCPs with a one-stop shop for evidence-based information and education on MM, along with opportunities for peer networking
- Face-to-face and virtual meeting support to disseminate data (eg congress symposia)

- Case-based educational materials that help translate evidence-based data into practical clinical application in various formats (text, audio, video)
- Resources for medical science liaisons to support drug product education for HCPs

Summary

MM is a devastating, rare relapsing-remitting haematological cancer with an unpredictable nature that can have a severe physical and emotional impact on those affected by it. Therefore, a good relationship between patients with MM and their HCPs is critical for successful patient outcomes, with communication forming an integral part in building a strong alliance. Support solutions for both HCPs and patients will help develop an enduring partnership, make consultations more efficient and effective, and enhance the patient experience.

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