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# PATIENT REPORTED OUTCOMES IN OPTIMIZING MYELOMA PATIENTS' HEALTH-RELATED QUALITY OF LIFE

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**OBJECTIVE:** *To review the current state of evidence for the use of patient-reported outcomes (PROs) and health-related quality of life (HRQoL) in optimizing best supportive care for patients with multiple myeloma (MM).*

**DATA SOURCES:** *Peer-reviewed journal articles, research reports, state of the science papers, and clinical guidelines.*

**CONCLUSION:** *The diagnosis and treatment of MM negatively impacts an individual's HRQoL. Validated self-report tools that assess HRQoL and other PROs provide an insight into how the treatment or disease is impacting the individual, enabling early recognition of physical and emotional concerns. There is a growing body of evidence to support the use of PROs in assessing HRQoL in MM in clinical care.*

**IMPLICATIONS FOR NURSING PRACTICE:** *There is a clear benefit for nurses to utilize PROs for patients with MM in order to obtain an understanding of how the treatment effects HRQoL. Thoughtful use of PRO measures can enable nurses to individualize supportive care interventions to meet the specific needs of the patient, and facilitate timely access to optimal symptom support.*

**KEY WORDS:** *multiple myeloma, health-related quality of life, patient-reported outcome, PRO, patient-reported outcome measure, PROM, supportive care.*

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**M**ultiple myeloma (MM) is a rare, complex, and debilitating cancer of the bone marrow plasma cells, characterized by significant disease morbidity, including bone destruction, and renal and immunological impairment.<sup>1</sup> With approximately 114,250 people diagnosed worldwide each year,<sup>2</sup> MM is a relatively rare cancer, accounting for around 1.2% of all cancer diagnoses. MM is a cancer of the older person, and the number of cases is increasing due to improvements in overall survival (OS) and an aging population.<sup>3</sup> New therapeutic modalities have improved the length of survival for those diagnosed with MM, but it remains an incurable disease.

A range of treatment approaches are utilized over the course of a patient's illness. Treatment includes the use of high-dose therapy (HDT) with autologous stem cell transplantation (ASCT), alkylating agents, corticosteroids, proteasome inhibitors, immune modulators, and monoclonal antibodies. Alongside treatments to control the underlying MM, a range of supportive measures such as radiotherapy, analgesics, antimicrobials, antithrombotics, vaccinations, blood product support, and bisphosphonate therapies are commonly indicated.<sup>4,5</sup> For patients to benefit from improvements in OS and sustained remissions, they may require several lines of multi-agent therapy over an increased length of time. The common disease trajectory in MM consists of alternating periods of active disease that require treatment, and other times that require either maintenance therapy or close observation.<sup>6</sup>

MM is a heterogeneous disease in terms of its presentation and outcomes, and the disease trajectory does not follow a linear path. While it is widely understood that disease progression and further courses of therapy will be required, the time lines cannot be predicted for any individual patient. The primary goals of treatment are controlling the underlying disease, prolonging survival, and maximizing health-related quality of life (HRQoL).<sup>1,7,8</sup> Improving overall health outcomes for patients with MM is achieved through a combination of treatment approaches, delivery of supportive measures, and provision of targeted supportive care.

Although modern treatment approaches have positively influenced OS, it has come at some considerable cost to the patient. The burden of MM-related symptoms, treatment related toxicities, and financial and psychosocial effects contribute to increased morbidity and mortality of MM patients and adversely impact HRQoL.<sup>1,9-15</sup> The observed differences

in HRQoL throughout the course of disease are complex and sometimes counterintuitive.<sup>15-17</sup>

The goal of health care is to restore or preserve function and well-being relating to HRQoL. It is important for nurses to understand the concept of quality of life (QoL), and what this means for patients with MM. This article discusses what is known about the impact of MM on HRQoL and patient-reported outcomes (PROs), what approaches to measuring and monitoring are available, and how nurses can utilize such instruments to improve outcomes for patients and their families.<sup>18</sup>

As MM is a chronic, debilitating cancer, patients with MM experience a high prevalence of symptoms relating to disease- and treatment-related toxicities. PROs describe the range of experience's, perspectives, and HRQoL concerns of the individual and these data play an important role in health care. An increasing range of PRO measures (PROMs) are available to assess for global QoL, symptoms, and supportive care needs. The systematic utilization of PROMs by nurses can allow a greater understanding of the subjective experience of patients and facilitate supportive care to improve outcomes in a patient-centered approach.

## QUALITY OF LIFE

QoL is a complex concept, meaning different things to different people depending on the specific circumstances and purpose of its application. Therefore it does not have a universal definition or a standard for its measurement, yet it must be defined in order to be clinically useful.<sup>19</sup>

In its broadest sense, QoL covers aspects of life that are beyond the scope of health care, such as living standards, housing, education, employment, and the environment. HRQoL focuses on how an individual experiences QoL in ill health. An accepted definition that is useful for clinical trials and health services research is HRQoL is a multidimensional construct encompassing perceptions of both positive and negative aspects of physical, emotional, social, and cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms produced by a disease or its treatment.<sup>20</sup>

Implicit in this definition is that illness compromises not only the biological integrity, but also the psychological, social, and economic well-being of an individual.<sup>21</sup> Exploration of HRQoL must incorporate more than the physical, but include areas

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