

# A Qualitative Study of the Experiences of Living With Multiple Myeloma

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**PURPOSE:** To explore the ways in which multiple myeloma affects an individual's life in the modern treatment era.

**PARTICIPANTS & SETTING:** 15 individuals with multiple myeloma and 10 clinicians were recruited from two academic medical centers in the southeastern United States.

**METHODOLOGIC APPROACH:** Semistructured interviews were conducted with individuals with multiple myeloma and clinicians to explore the effect of a multiple myeloma diagnosis and treatment on individuals' lives. Transcribed interviews were analyzed using conventional content analysis.

**FINDINGS:** The following four themes emerged from the analysis: treatment without end, social impacts and isolation, ongoing financial pressure, and relationship impacts.

**IMPLICATIONS FOR NURSING:** The treatment journey for those with multiple myeloma can be lifelong and may require frequent visits to an oncologist and, potentially, many successive lines of therapy. Life effects are far-reaching and long-term. Nurses should be aware of the interprofessional resources to help meet these individuals' needs. With thorough assessment, care planning, and education, nurses can play a key role in mitigating the negative effects of multiple myeloma and its treatment.

**KEYWORDS** multiple myeloma; treatment; survival; symptom burden; quality of life

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Multiple myeloma is the second most common hematologic malignancy in the United States, with 32,270 new diagnoses and 12,830 deaths estimated in 2020 (Siegel et al., 2020). Incidence is slightly higher in men than in women and almost twice as high in African Americans than in other races (National Cancer Institute, 2020). Median age of onset is 69 years, and the five-year survival rate is 53% (National Cancer Institute, 2020). Multiple myeloma's malignant plasma cells proliferate unregulated in the bone marrow, causing weakened bones, fractures, pain, anemia, hypercalcemia, and renal insufficiency (Gasparetto & Sivaraj, 2019). Multiple myeloma-directed treatment can help to reduce disease-related symptoms while introducing side effects such as fatigue, nausea, and peripheral neuropathy (McCullough et al., 2018; Raza et al., 2017).

Those living with multiple myeloma have seen median survival extend from two years in the year 2000 to more than five years currently (American Cancer Society, 2020). Younger individuals with multiple myeloma have seen median survival extend to greater than 10 years (Costa et al., 2017; Morgan & Rasche, 2017). Although long considered incurable, some have argued that cure is possible in light of the long and deep remissions experienced by some with multiple myeloma (Barlogie et al., 2014; Ravi et al., 2018). Improvements in survival have coincided with the rapid introduction of new therapies and changes in treatment patterns (Kumar, 2017). This modern treatment era began in the late 1990s and earlier 2000s with the introduction of immunomodulatory agents (thalidomide, lenalidomide) and the proteasome inhibitor bortezomib as effective anti-myeloma therapies (Kane, 2003; Singhal et al., 1999). Initial treatment often involves a three-drug induction regimen followed by high-dose chemotherapy and autologous stem cell rescue (Kumar et al., 2018). Maintenance therapy post-transplantation