

The First Year Diagnosis Burden of Multiple Myeloma

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ABSTRACT

Multiple Myeloma (MM) is associated with significant morbidity and mortality, and Newly Diagnosed Multiple Myeloma (NDMM) is highly burdensome for patients and caregivers in the first year after treatment initiation. It is vital to understand early how the various aspects of the disease interrelate to the impact on the health and economic outcomes of patients and caregivers to improve management of the disease from diagnosis to treatment related decisions.

Keywords: Newly diagnosed multiple myeloma; Patients; Caregivers

DESCRIPTION

Multiple Myeloma (MM) is the most common hematological malignancy next to leukemia and remains an incurable disease of which patients experience significant mortality and morbidity [1]. Newly Diagnosed Multiple Myeloma Patients (NDMM) now has various therapeutic options which have proven effective in both Transplant Eligible (TE) and Transplant Non-Eligible (TNE) patients [2]. In spite of these advances in treatment, NDMM and their caregiver's still experience significant burden especially within the first year of being treated [3]. There is a dearth of literature regarding the Burden of Illness (BoI) experienced by patients and their caregivers, particularly within the first year of diagnosis. The study by Gatapoulou et al, was the first published study analyzing the BoI among TE and TNE NDMM patients and their caregivers from France, Germany, Italy, and Spain within the first year after diagnosis with a prospective cross-sectional design [4]. Caregivers in the study referred to "people who look after family members, friends, neighbors, or others because of long-term physical or mental ill health or disability, or care needs related to old age". In the study, the majority of NDMM patients were older than 65 years, unemployed, and living with a caregiver and self-described as healthy. The NDMM patients, (especially among TNE patients) were also reported to have experienced an increase in pain and opioid use, and loss of

independence in performing their day-to-day activities while Health-Related Quality of Life (HRQoL) and overall health status were stable [4]. With regards to healthcare costs, direct medical costs were highest at the 3rd month post diagnosis, and hospital admissions and visits to specialists were of great cost to patients. Among TNE patients, out-of-pocket expenditures were increased due to home adaptation. With regards to costs of productivity loss, patients who worked spent a median 0 hours in the office at all-time points [4]. Caregivers, at the end of the first-year post diagnosis developed anxiety, depression, or stress. Among caregivers who worked, productivity was low at month 0 and a greater time burden was reported in caregivers of TNE patients compared to TE [4]. However, in Gatapoulou et al, costs derived from using health and social care resources, while results relating to productivity loss relied on patients' and caregivers' recollection of usage. These were based on only a small number of NDMM employed patients, predominantly due to the age of participants. In addition, the costs of treatment to the patients were not recorded [4]. Further research is needed to collect data on costs in a prospective manner, and samples should include more employed patients to interpret the impact on costs and productivity loss in a more complete manner.

Burden of Illness (BoI) Gatapoulou et al, collected information from the date of diagnosis as reported in hematologist/hemato-

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Received: 15-Mar-2023, Manuscript No. JLU-23-22216; **Editor assigned:** 20-Mar-2023, Pre QC No. JLU-23-22216 (PQ); **Reviewed:** 10-Apr-2023, QC No. JLU-23-22216; **Revised:** 17-Apr-2023, Manuscript No. JLU-23-22216 (R); **Published:** 24-Apr-2023, DOI: 10.35248/2329-6917.23.11.318

Citation: Iraqi W, Falope O, Morgan K, Magarotto V (2023) The First Year Diagnosis Burden of Multiple Myeloma- A Short Commentary. J Leuk. 11:318.

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oncologist questionnaire [4]. But other sources showed that diagnosis delays are central to reduce the BOI, improve quality of life, and to speed-up MM patient access to the right treatment, with a final improvement in their overall survival. Diagnosis delays are usually as a result of factors such as non-specificity and rarity of MM symptoms, health system issues (wrong referrals, lack of doctor's appointment), sociodemographic factors (lack of access to tests, geographic inequalities) and epidemics/pandemic such as the COVID-19 outbreak [5]. In this frame, there could be two areas of intervention. First, the central role of the General Practitioner (GP) and the need of their awareness of the disease. Different studies conducted both in US and Europe, reported that MM is often not included in the differential diagnosis workup when patients present with symptoms such as fatigue, bone pain, or anemia from the GPs [6]. In an English study, almost 50% of patients who were diagnosed with NDMM had a presenting symptom of bone pain about 7 months before to MM diagnosis. Investigations that evaluated the Carbapenem-Resistant *Acinetobacter Baumannii* (sCRAB) criteria, such as urine and blood, and other specific tests targeting imaging, were underused [7]. Early recognition of myeloma clinical features and optimized use of investigations in primary care may potentially expedite MM diagnosis.

The COVID-19 pandemic also exacerbated this situation. MM patients diagnosed during the pandemic were more likely to present with more advanced disease at the emergency room [8]. Advanced disease is characterized by extramedullary disease and lytic lesions which are associated with increased use of opiates, decreased quality-of-life scores, impaired mobility, and increased healthcare costs. 8 Patients also experienced an impact on treatment, daily life and emotionally, evidenced by reduced access to hospitals, restrictions from the pandemic and anxiety respectively [9].

These delays can have substantial and long-lasting complications that can impact patients' survival, treatment choices, mental health, quality of life, finances, careers, day to day activities and their relationships [5].

CONCLUSION

Among TNE patients, out-of-pocket expenditures were increased due to home adaptation. With regards to costs of productivity

loss, patients who worked spent a median 0 hours in the office at all-time points. NDMM is highly burdensome for patients and caregivers in the first year after treatment initiation and more insights need to be generated also considering the potential impact of delayed diagnosis to support resource allocation decision-making and broader treatment value decisions.

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