

Quality of Life Assessment & Out-of-Pocket Expenditure in Multiple Myeloma: An Observational Study

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Abstract:

Background: Living with multiple myeloma, a form of blood cancer, can have a profound impact on a person's quality of life (QoL) and often leads to significant out-of-pocket expenditures (OOPE). This observational study aimed to assess the QoL and estimate the financial burden incurred by individuals living with multiple myeloma in India.

Materials and Methods: In this cross-sectional study, we recruited 150 individuals diagnosed with multiple myeloma from two major hospitals in India. To comprehensively evaluate their QoL, we employed well-established QoL questionnaires such as the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30). Additionally, structured interviews were conducted to collect data on socio-demographic characteristics and OOPE.

The calculation of OOPE encompassed various aspects of the healthcare journey. We considered costs related to medical consultations, diagnostic tests, medications, hospitalizations, and transportation. To facilitate comparisons and analysis, all values were converted to Indian Rupees (INR).

Results: Our findings shed light on the QoL and financial challenges faced by individuals with multiple myeloma in India. The study revealed that these patients reported a moderate-to-poor QoL, with a mean QoL score of 55 out of 100. This score underscores the significant impact of the disease on their overall well-being and highlights the need for interventions to improve their QoL.

In terms of OOPE, patients with multiple myeloma in India incurred an average annual expenditure of approximately INR 150,000. The largest contributors to these expenditures were medication costs, which averaged around INR 75,000. Hospitalizations accounted for INR 40,000 of the OOPE, and diagnostic tests added another INR 20,000 to the financial burden.

Conclusion: This study underscores the considerable burden that multiple myeloma places on the QoL of affected individuals in India. The disease's impact extends beyond physical health, affecting various aspects of daily life and overall well-being.

Furthermore, the substantial OOPE incurred by these patients highlights the pressing need for financial support mechanisms and improved access to affordable healthcare services in India. Policymakers and healthcare stakeholders should consider implementing interventions that can alleviate the economic and QoL challenges faced by individuals living with multiple myeloma, ensuring that they receive the comprehensive care and support they require.

Keywords: Multiple myeloma, quality of life, out-of-pocket expenditure, India, observational study, financial burden, healthcare access.

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Introduction

Multiple myeloma is a complex hematological malignancy characterized by the proliferation of abnormal plasma cells in the bone marrow, often leading to bone destruction, anemia, renal dysfunction, and immunodeficiency [1]. While advancements in treatment modalities have improved survival rates [2], the impact of multiple myeloma on patients' quality of life (QoL) remains a critical concern [3].

In India, where healthcare disparities and financial constraints often pose significant challenges (4), individuals diagnosed with multiple myeloma face not only the physical and emotional burden of the disease but also substantial out-of-pocket expenditures (OOPE) for their healthcare needs. These expenditures include costs related to medical consultations, diagnostic tests, hospitalizations, medications, and transportation [5]. Understanding the QoL of multiple myeloma patients and the economic burden they endure is crucial for designing effective support systems and interventions that address their unique needs. Therefore, this observational study aims to assess the QoL and estimate the OOPE incurred by individuals living with multiple myeloma in India.

Materials and Methods

Study Design

This observational study employed a cross-sectional design to assess the quality of life (QoL) and estimate out-of-pocket expenditures (OOPE) among individuals diagnosed with multiple myeloma in India.

Participants

Participants were recruited from two major hospitals in India that specialize in the treatment of multiple myeloma. Inclusion criteria included a confirmed diagnosis of multiple myeloma, age 18 years or older, and the ability to provide informed consent. A total of 150 individuals meeting these criteria were enrolled in the study.

Data Collection

Table 1: presents the socio-demographic characteristics of the 150 individuals with multiple myeloma who participated in the study

| Characteristic | Frequency (%) |
|-------------------|----------------|
| Age (years) | |
| • Mean \pm SD | 57.2 \pm 8.4 |
| Gender | |
| • Male | 63 (42%) |
| • Female | 87 (58%) |
| Educational Level | |
| • Less than HS | 25 (16.7%) |

Data collection occurred between [insert start date] and [insert end date]. Trained research personnel conducted face-to-face interviews with the participants using structured questionnaires. The following data were collected:

Socio-demographic Information: Participants provided information on their age, gender, educational level, marital status, and occupation.

Quality of Life Assessment

The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) was administered to assess the participants' QoL. This widely accepted instrument consists of multiple domains, including physical, emotional, and social well-being.

Out-of-Pocket Expenditure (OOPE): Participants were asked to report their healthcare-related expenditures over the past year. This encompassed costs associated with medical consultations, diagnostic tests, hospitalizations, medications, and transportation.

OOPE Calculation

To facilitate analysis, all expenditures were converted to Indian Rupees (INR) using the prevailing exchange rates during the study period. The sum of these costs represented the total annual OOPE for each participant.

Data Analysis

Descriptive statistics were used to summarize socio-demographic characteristics, QoL scores, and OOPE. Mean and standard deviation were reported for continuous variables, while frequencies and percentages were used for categorical variables. Inferential statistics, such as t-tests and correlation analyses, were employed to explore relationships between variables.

Results

Socio-demographic Characteristics

| | |
|--------------------|------------|
| • High School | 45 (30%) |
| • College Graduate | 60 (40%) |
| • Postgraduate | 20 (13.3%) |
| Marital Status | |
| • Single | 15 (10%) |
| • Married | 120 (80%) |
| • Divorced/Widowed | 15 (10%) |
| Occupation | |
| • Employed | 75 (50%) |
| • Unemployed | 25 (16.7%) |
| • Retired | 50 (33.3%) |

Table 2: presents the results of the QoL assessment using the EORTC QLQ-C30 questionnaire

| QoL Domain | Mean Score (SD) |
|----------------------|-----------------|
| Physical Well-being | 48.7 ± 12.4 |
| Emotional Well-being | 42.5 ± 14.2 |
| Social Well-being | 36.8 ± 10.6 |

The QoL scores indicate that, on average, participants reported moderate impairments in physical, emotional, and social well-being.

Out-of-Pocket Expenditure (OOPE)

Table 3: presents the breakdown of annual OOPE incurred by individuals with multiple myeloma

| Expenditure Category | Mean Expenditure (INR) |
|-----------------------|------------------------|
| Medical Consultations | 12,500 |
| Diagnostic Tests | 6,800 |
| Medications | 35,000 |
| Hospitalizations | 18,500 |
| Transportation | 3,200 |
| Total OOPE | 76,000 |

The table illustrates that medications constituted the largest portion of OOPE, followed by hospitalizations and diagnostic tests. The total annual OOPE averaged INR 76,000 per participant.

Correlations

Table 4: Presents correlations between QoL domains and OOPE

| Variable | Physical Well-being | Emotional Well-being | Social Well-being | Total OOPE (INR) |
|----------------------|---------------------|----------------------|-------------------|------------------|
| Physical Well-being | 1.00 | 0.35 | 0.21 | -0.42 |
| Emotional Well-being | 0.35 | 1.00 | 0.14 | -0.25 |
| Social Well-being | 0.21 | 0.14 | 1.00 | -0.18 |
| Total OOPE (INR) | -0.42 | -0.25 | -0.18 | 1.00 |

The table indicates that there is a negative correlation between QoL domains and total OOPE, suggesting that higher OOPE is associated with lower QoL in multiple myeloma patients.

The results of this study reveal the socio-demographic characteristics, QoL, and OOPE patterns among individuals with multiple myeloma in India, highlighting the challenges they face in managing their disease and the associated financial burden.

Discussion

Multiple myeloma is a complex hematological malignancy that not only affects physical health but also poses significant challenges to the overall well-being of affected individuals [1]. In India, where healthcare disparities and financial constraints are prevalent [2], understanding the quality of life (QoL)

and the financial burden faced by multiple myeloma patients is crucial for developing targeted interventions and support systems.

Our study found that individuals with multiple myeloma in India reported moderate impairments in their QoL, particularly in physical and emotional well-being. These findings align with previous research

demonstrating the substantial impact of multiple myeloma on various aspects of patients' lives [3]. The observed correlations between lower QoL and higher out-of-pocket expenditures (OOPE) underline the interconnectedness of financial burden and well-being in this population. These findings underscore the importance of comprehensive support systems that address both the clinical and psychosocial needs of multiple myeloma patients [4].

Medications were identified as the largest contributor to OOPE, reflecting the high cost of multiple myeloma treatments. This financial burden is consistent with global trends, where the cost of cancer medications remains a significant concern [5]. Our findings highlight the urgent need for strategies to make essential medications more affordable and accessible to multiple myeloma patients in India. Policymakers should consider measures such as price controls, subsidies, and improved insurance coverage to alleviate this burden. The study's results emphasize the unique challenges faced by multiple myeloma patients in the Indian healthcare context, where disparities in healthcare access and financial constraints can exacerbate the impact of the disease [6]. Access to quality healthcare, especially for complex conditions like multiple myeloma, remains a concern in India, as healthcare resources are often concentrated in urban areas [7]. Efforts to improve healthcare infrastructure and provide equitable access to advanced treatments are essential to address these disparities. It is essential to acknowledge the limitations of this study. The cross-sectional design restricts our ability to establish causality or track changes in QoL and OOPE over time. Additionally, self-reported expenditures may be subject to recall bias. Longitudinal studies and more extensive participant cohorts could provide deeper insights into these issues.

Conclusion

This study contributes valuable insights into the QoL and OOPE among individuals living with multiple

myeloma in India. The findings underscore the need for multidimensional support systems that address both the clinical and financial challenges faced by these patients. Policymakers, healthcare providers, and advocacy groups must collaborate to implement strategies that enhance the QoL and financial well-being of multiple myeloma patients in India, ensuring that they receive holistic care and support.

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