Quality of life assessment & out-of-pocket expenditure in multiple myeloma: An observational study

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Background & objectives: Prognosis of patients with multiple myeloma (MM) has improved significantly in the past two decades. However, the symptoms burden is high at onset and treatment is generally prolonged with significant financial burden. This study was undertaken to assess the quality of life (QoL) and to analyse out-of-pocket expenditure (OOPE) incurred on MM patients being treated at a tertiary care cancer centre in north India.

Methods: This observational, cross-sectional study included 116 patients (aged >18 yr) of MM (both newly diagnosed and those with recurrent disease). For QoL assessment, European Organisation for Research and Treatment of Cancer (EORTC)-validated questionnaire (EORTC QLQ C 30 version 3.0) and disease-specific QLQ MY20 were used. For assessing OOPE incurred on treatment, the National Sample Survey Organisation (NSSO) questionnaire was used.

Results: Bone pains (68.1%), fatigue (59.7%) and dyspnoea (54.6%) were common symptoms. The mean global health status/QoL score was 59.62±19.21. International Staging System (ISS) score correlated with global health status score, and gastritis was the main adverse effect. QoL score showed negative correlation to side effects of treatment (−0.53) of MY20 domain. On multivariate analysis, ISS stage (<0.001) and adverse effects of treatment (P=0.02) were predictive factors. The median OOPE was ₹ 7900 (IQR, ₹ 4950-13,550) towards medical and ₹ 1150 (IQR, ₹ 500-3100) for non-medical expenses for the past one month.

Interpretation & conclusions: Regular assessment of QoL in the clinical management of multiple myeloma patients has the potential of improving treatment outcomes. Measures to reduce out-of-pocket expenditure may improve treatment compliance.

Key words Economic burden - multiple myeloma - OOPE - quality of life

Multiple myeloma (MM) is a disease of malignant plasma cell and is the second most common haematological malignancy after non-Hodgkin’s lymphoma. Incidence of myeloma is higher in industrialized nations¹ (2-4 per 100,000 population) and lower in Asia (1.7 per 100,000)². In India, the incidence is 1.2 per 100,000 with males being affected more [1.36, 95% confidence interval (CI) 1.29-1.45]
compared to women (0.99, 95% CI 0.93-1.07)\(^3\). There is heterogeneity in the incidence of MM across India. A study of 1916 cases from 27 population-based cancer registries revealed highest incidence in Southern zone (44.9%), followed by Northern zone (20.5%), West zone (19.4%), Northeast zone (9.6%), East zone (3.5%) and 2.1 per cent in Central zone\(^4\).

There has been significant improvement in the survival of myeloma patients aged ≤65 yr in the past two decades, attributed to the introduction of novel agents (immunomodulators such as thalidomide, lenalidomide; proteasome inhibitor such as bortezomib), high-dose chemotherapy, followed by autologous stem cell transplantation (ASCT), and use of maintenance therapy\(^2\). Currently, standard treatment approach for a newly diagnosed patients of myeloma (who do not have major comorbidity and are <65-70 yr of age) includes initial induction therapy with three drugs (typically bortezomib plus lenalidomide or thalidomide and dexamethasone for 4-6 cycles). Those having good response (complete/very good partial/partial response) are counselled for ASCT followed by maintenance therapy – usually lenalidomide in low doses for three years. Those who are elderly or have major comorbidities are given induction with two drug combinations (e.g. bortezomib+dexamethasone or lenalidomide+dexamethasone) for 8-12 cycles followed by maintenance therapy. Despite initial good responses in most patients relapses are frequent, with progression-free survival of 32-36 months, for those responses in most patients relapses are frequent, with progression-free survival of 32-36 months, for those who undergo ASCT compared to less than two years for others\(^5\). The factors such as International Staging System (ISS) stage (stage III), high-risk cytogenetics, more than one line of induction therapy and presence of extramedullary disease are considered to be predictors of relapse\(^5\). Thus, in a typical case of MM, the disease course is characterized by remissions and relapses\(^5\). With each relapse, there is a reduction in the response rate as well as in the duration of response with increase in therapy-related adverse effects with impaired quality of life (QoL). Therefore, controlling symptoms and improving QoL are important considerations in the management of MM patients.

In addition to QoL, out-of-pocket expenditure (OOPE) is another important aspect in MM. The National Sample Survey Organisation (NSSO) 75\(^{th}\) Round Annual Report has shown that the average medical expenditure per hospitalization is different in different types of hospital with average expenditure being ₹61,216 (being lower in public hospitals ₹22,520 compared to ₹93,305 in private hospitals\(^6\). As per multicentric study on the treatment cost among cancer patients in public hospitals from five different States (Kerala, Maharashtra, Rajasthan, West Bengal and Mizoram), 75 per cent patients had financial problem and 44 per cent had to travel long distances to reach to the hospitals\(^7\). Free diagnosis and financial help towards travel expenses were suggested to improve compliance to therapy for patients belonging to economically weaker sections\(^7\).

The present study was thus conducted to assess the QoL and economic burden among MM patients being treated in a tertiary care hospital in north India. The factors affecting health-related QoL also were explored. The OOPE incurred on the treatment to understand financial difficulties faced by these patients and their families was also evaluated.

**Material & Methods**

This was an observational, cross-sectional study conducted in the outpatient department (OPD) setup of the department of Medical Oncology, BR Ambedkar Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi, India, between November 15, 2019 and January 30, 2020. Consecutive patients of MM attending myeloma clinic were screened for inclusion criteria. Those with definitive diagnosis of MM (based upon serum and/or urine electrophoresis, skeletal survey and bone marrow plasmacytosis), age >18 yr, patient undergoing active treatment with novel agents-based induction with or without radiotherapy or those who have undergone ASCT and currently on salvage therapy due to relapse or on maintenance therapy or patients with relapse and currently on salvage treatment were included. Those with major psychiatric disorder (patients with bipolar disorder, major depressive disorder and schizophrenia) were excluded. Severely ill patients (those who were bed ridden or unable to communicate to the interviewer due to progressive disease) were also excluded.

The study was approved by Institutional Ethics Committee (IEC-675/6.09.2019, RP-41/2019). Before taking consent, the participants were explained the purpose of the study and implications in detail. The participation was voluntary, and participant could exit from the study at any point of time. Patient signed an informed consent form before data collection which was done in private and confidentiality was maintained.

The study outcomes QoL and cost of treatment were quantitative. After review of literature in the
Indian context\(^8\), the standard deviation (SD) was taken as 21, alpha error as five per cent and taking precision at four per cent and after adjusting for 10 per cent non-response rate, the sample size was calculated to be 116.

**Data collection and tools**

Patients and disease-specific details: Patient’s demographic details including age, gender, marital status, education, occupation, household expenditure, state and source of finance were recorded. Household type classified as rural and urban were confirmed by patients’ addresses from the Aadhar card. Patients from urban areas generally were in either government jobs, school/police or working as labourer in industry/trade and a few were daily-wagers. Those from rural areas were primarily in agriculture (either as farmer or labourer) and a few were in other jobs. Baseline characteristics and treatment modalities, line of treatment, response to treatment and co-morbidities were recorded (Table I).

**Quality of life (QoL):** European Organisation for Research and Treatment of Cancer (EORTC) QoL questionnaire (QLQ C 30 version 3.0) was used\(^9\). This has 30 items— five functioning scales (physical, psychological, role, cognitive and social), three symptom scales (fatigue, pain, nausea and vomiting) and one global health status/QoL scale and the remaining six items to assess symptom. This questionnaire has been validated and translated into 110 languages including Hindi and eight other Indian languages and has been used in more than 3000 studies worldwide\(^9\). It was an interview-based questionnaire.

**Interpretation:** For global health status and functional status, a high score indicates better QoL, while a high score for symptoms and other six items indicates poor QoL. Raw score was estimated by taking average of the items score and then using a linear transformation to standardize raw score which ranges from 0 to 100\(^1\).

For disease-specific QoL: MY20 questionnaire was used which is a validated tool available in both English and Hindi and has specified 20 items. These include four domains future perspective, body image, disease symptom and side effect of treatment\(^1\). Scoring procedure was similar to QLQ C30.

**Out-of-pocket expenditure (OOPE):** The NSSO questionnaire\(^1\) was used to get details about the OOPE incurred on treatment. The questionnaire

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**Table I.** Socio-demographic characteristics of the patients (n=116)

| Patients characteristics | n (%) |
|--------------------------|-------|
| Age (yr), median (range)  | 59 (21-78) |
| Gender                   |       |
| Male                     | 88 (75.9) |
| Female                   | 28 (24.1) |
| State                    |       |
| Delhi                    | 25 (21.6) |
| Outside Delhi            | 91 (78.4) |
| Marital status           |       |
| Married                  | 106 (91.4) |
| Unmarried                | 5 (4.3) |
| Widow                    | 5 (4.3) |
| Education                |       |
| Uneducated               | 16 (13.8) |
| Secondary education      | 55 (47.4) |
| Graduation/above         | 45 (38.8) |
| Occupation               |       |
| Self employed            | 26 (22.4) |
| Salary earning           | 22 (19) |
| Retired                  | 22 (19) |
| Others                   | 46 (39.6) |
| Household type           |       |
| Urban                    | 50 (43.1) |
| Rural                    | 66 (56.9) |
| Total household expenditure (in ₹) | 20,000 (2000-70,000)* |
| Comorbidities            |       |
| No comorbidities         | 57 (49.1) |
| 1 comorbidity            | 35 (30.2) |
| More than 1 comorbidities | 24 (20.7) |
| ISS staging              |       |
| I                        | 18 (15.5) |
| II                       | 23 (19.8) |
| III                      | 75 (64.7) |
| Time since diagnosis (yr) | 2.5 (0.2-18.3)* |
| Treatment                |       |
| Induction chemotherapy    | 41 (35.4) |
| Maintenance therapy       | 67 (57.8) |
| Radiotherapy              | 1 (0.8) |
| Observation               | 7 (6.03) |
| Treatment medication      |       |
| 3-drug regimens           | 43 (37.0) |
| 2-drug regimens           | 46 (39.7) |

*Contd...*
includes socio-demographic and treatment details. These were noted from patients’ records. Questions on medical expenses (doctor fee, cost of diagnostics, investigations and medicines) and non-medical expenses (transport, food, lodging expenses) were noted. This also included wages loss per day and total wage loss was calculated based on the number of days patient had to visit for diagnostic tests and OPD visit. The data were analysed using STATA software 15.1 version (StataCorp LLC, Stata Statistical Software: Release 15, College Station, TX, USA).

Statistical analysis: Descriptive analysis of QoL score of all 30 items from QLQ C 30 and 20 items of disease-specific from MY 20 was done using means and SD. Cost of treatment was calculated as median and interquartile range (IQR). The categorical factors such as socio-demographic and treatment characteristics were analyzed as frequency and percentage and continuous variables as mean/median and SD/IQR. For QoL assessment, EORTC-QoL proforma was used to compare the QoL score of myeloma patient in all stages. Univariate analysis for each factor (socio-demographic, treatment characteristics) was done using ANOVA/linear regression. Multivariate analysis was done using linear regression to adjust for confounding effect.

Results

A total of 116 patients were eligible for analysis. Patients’ baseline characteristics are given in Table I. The median age of the patients was 59 yr, ranging from 21 to 78 yr and 24 per cent were females; 64.7 per cent of patients had ISS stage III. Myeloma subtypes included IgG (kappa and lambda) 51.7 per cent, IgA (kappa and lambda) 8.6 per cent, and light chains (kappa and lambda type) in 25 per cent of patients. The median time from onset of symptoms to diagnosis was 30 months, ranging from two to 219 months and 20.7 per cent had two or more comorbidities; most common were hypertension (30.2%), diabetes mellitus (18.1%) and hypothyroidism (11.2%).

Income details: Ninety one (78.4%) patients were from outside Delhi; this included patients from neighbouring States of Uttar Pradesh (29.3%), Bihar (20.7%) and Haryana (12.9%). The median household expenditure was ₹20,000 (IQR, ₹2000-70,000); for those from urban area, it was ₹25,000 (IQR, ₹3000-70,000), while for patients from rural areas, median household expenditure was ₹20,000 (IQR, ₹2000-60,000).

QoL

QLQ C 30: The scores for all domains ranged from 0 to 100. The total mean global health status score including health and QoL was 59.6±19.2. On comparison with
EORTC reference score for myeloma, the global health status/QoL, functional scale in our study was higher and symptom scale showed lower score than the reference score (Table II). The highest symptom score was observed for pain (39.8) and lowest for diarrhoea being 3.2. This was followed by fatigue (defined as need to take rest, feeling weak and tired) which was experienced by 59.7 per cent. Nausea and vomiting were experienced by 16.4 and 8.7 per cent patients, respectively.

QLQ MY 20: The scores for myeloma in four domains were as follows: disease symptoms 27.87±25.1, side effect of treatment 15.61±12.6, body image 98.56±6.8 and future perspective 78.2±25.7. The most common site of pain was generalized bone pains; back and hip pain in 68.1 and 53.5 per cent patients, respectively and pain in arm and shoulder in 34.5 per cent of patients. Most common adverse effects reported by the patients were paraesthesia tingling sensation in hands and feet in 57.8 per cent, followed by burning of eyes or sore eyes in 38.8 per cent and restlessness in 34.5 per cent of patients. Only five per cent patients felt less attractive due to treatment. About half (55.2%) of patients were worried about their health in future and 40.6 per cent were worried about dying. QoL score for induction chemotherapy was 54.4±20.8 and for maintenance therapy, it was 61.6±16.5. The QoL score was higher for complete responders 72.8±22.6, compared to those with partial response 58±17.5 and progressive disease 44.4±34.7 (Table III).

Correlation between QoL and QLQ MY 20: The global health status/QoL score with four items of QLQ MY 20 were analysed for correlation. The correlation ranged from 0 (no correlation) to 1 (maximum correlation). Future perspective (0.41) and body image (0.27) showed positive correlation while side effect of treatment (−0.53) and disease symptoms (−0.47) presented negative correlation.

Factor associated with global health status/QoL score: On multivariate analysis, ISS stage (P<0.001) and adverse effects of treatment (P=0.02) were predictive factors (Table IV). The global health status score reduced by 23.7 units in stage II and 13.1 units in stage III compared to stage I (P<0.001). Similarly, global health status score reduced by 12.2 units for those with gastritis compared to patients who did not have (P=0.02).

Out-of-pocket expenditure: Table V provides data on OOPE incurred on treatment; 34 per cent of patients had taken treatment from outside before coming to our centre. Of these, 67 per cent have taken treatment in private institutions and rest in the government hospitals. Further, eight per cent patients were central government health scheme beneficiary.

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**Table II. European Organisation for Research and Treatment of Cancer (EORTC) Quality of life (QoL) C-30 score**

| Domains | Patients’ score, mean±SD | EORTC reference value for QLQ C-30 for myeloma |
|---------|--------------------------|-----------------------------------------------|
| Global health status/QoL | 59.6±19.2 | 55.70 (22.8) |
| Functional scale | | |
| Physical functioning | 68.1±24.0 | 67.7 (23.3) |
| Role functioning | 73.1±25.7 | 60.1 (33.4) |
| Emotional functioning | 81.9±21.0 | 71.3 (22.7) |
| Cognitive functioning | 78.9±23.2 | 78.1 (23.8) |
| Social functioning | 72.1±25.9 | 63.2 (31) |
| Symptom scale | | |
| Fatigue | 38.6±30.4 | 48.7 (26.7) |
| Nausea and vomiting | 5.5±13.7 | 10.5 (19.2) |
| Pain | 39.8±32.1 | 47.1 (33.6) |
| Dyspnoea | 26.1±35.4 | 26.0 (27.3) |
| Insomnia | 19.5±30.2 | 28.9 (30.6) |
| Appetite loss | 12.9±25.2 | 23.2 (30.2) |
| Constipation | 16.9±24.7 | 23.2 (29.9) |
| Diarrhoea | 3.2±12.4 | 9.6 (19.4) |
| Financial difficulties | 29.3±28.2 | 16.6 (26.6) |

QoL, quality of life; SD, standard deviation; QLQ, quality of life questionnaire

**Table III. Global health status related to different treatments and response to treatment**

| Treatment and response | n=116, n (%) | Global health status (mean±SD) |
|------------------------|--------------|--------------------------------|
| Treatment | | |
| Induction chemotherapy | 41 (35.3) | 54.4±20.8 |
| Maintenance therapy | 67 (57.8) | 61.6±16.5 |
| Others (radiotherapy + observation) | 8 (6.9) | 69.8±26.7 |
| Response to treatment | | |
| Complete response | 15 (12.9) | 72.8±22.6 |
| Very good partial response | 20 (17.3) | 60.4±14.5 |
| Partial response | 73 (62.9) | 58±17.5 |
| Stable disease | 5 (4.3) | 50±26.4 |
| Progressive disease | 3 (2.6) | 44.4±34.7 |
| Determinants                              | n=116, n (%) | Univariable analysis | P  | Multivariable analysis | P  |
|------------------------------------------|--------------|----------------------|----|------------------------|----|
|                                          |              | Crude $\beta$ coefficient (95 per cent CI) |     | Adjusted $\beta$ coefficient (95 per cent CI) |     |
| Age of patient (yr)                      |              |                      |    |                        |    |
| <60                                      | 60 (51.7)    | Reference            | 0.73| Reference              | 0.35|
| ≥60                                      | 56 (48.3)    | 1.2 (−5.8-8.3)       |     | 3.9 (−4.4-12.3)        |     |
| Gender of patient                        |              |                      |    |                        |    |
| Male                                     | 25 (21.6)    | Reference            | 0.97| Reference              | 0.85|
| Female                                   | 91 (78.4)    | −0.13 (−8.4-8.1)     |     | −0.9 (−10.7-8.9)       |     |
| Education of patient                     |              |                      |    |                        |    |
| Uneducated                               | 16 (13.8)    | Reference            | 0.26| Reference              | 0.68|
| Secondary education                      | 55 (47.4)    | 5.2 (−5.4-16.1)      |     | 0.3 (−10.2-10.8)       |     |
| Graduation/above                         | 45 (38.8)    | 8.9 (−2.1-19.9)      |     | −3.2 (−15.4-8.9)       |     |
| Occupation of patient                    |              |                      |    |                        |    |
| Self employed                            | 26 (22.4)    | Reference            | 0.08| Reference              | 0.12|
| Salary earning                           | 22 (19)      | 12.9 (2.1-23.8)      |     | 16.5 (2.6-30.4)        |     |
| Retired                                  | 22 (19)      | 8.01 (−2.8-18.8)     |     | 6.6 (−6.7-19.9)        |     |
| Others                                   | 46 (39.6)    | 2.9 (−6.2-12.12)     |     | 3.4 (−7.1-14)          |     |
| Marital status of patient                |              |                      |    |                        |    |
| Married                                  | 106 (91.4)   | Reference            | 0.35| Reference              | 0.30|
| Unmarried                                | 5 (4.3)      | 12.62 (−4.8-30.0)    |     | 12.4 (−4-28.8)         |     |
| Widow                                    | 5 (4.3)      | 0.96 (−16.4-18.4)    |     | −3.2 (−20.5-14.0)      |     |
| Household type of patient                |              |                      |    |                        |    |
| Urban                                    | 50 (43.1)    | Reference            | 0.002*| Reference           | 0.18|
| Rural                                    | 66 (56.9)    | −11.20 (−18.1--4.3)  |     | −5.9 (−14.7-2.8)       |     |
| Source of financing                      |              |                      |    |                        |    |
| Income                                   | 31 (26.72)   | Reference            | 0.06| Reference              | 0.21|
| Contribution by family                   | 67 (57.76)   | −4.9 (−13-3.2)       |     | 7.1 (−4.2-18.3)        |     |
| Others                                   | 18 (15.52)   | −11.2 (−24.2--2)     |     | −0.2 (−13.3-13)        |     |
| Time since diagnosis (in yr)             | 2.5 (4.5)    | 1.2 (0.3-2.2)        | 0.009| 0.7 (−0.3-1.7)        | 0.17|
| ISS staging                              |              |                      |    |                        |    |
| I                                        | 15 (12.9)    | Reference            | <0.001| Reference           | <0.001|
| II                                       | 20 (17.2)    | −24.3 (−35.5--13.1)  |     | −23.7 (−35--12.3)      |     |
| III                                      | 71 (61.3)    | −14.2 (−23.5--4.8)   |     | −13.1 (−22.9--3.2)     |     |
| Co-morbidities                           |              |                      |    |                        |    |
| No co-morbidities                        | 57 (49.1)    | Reference            | 0.99| Reference              | 0.96|
| 1 co-morbidity                           | 35 (30.2)    | 0.25 (−7.9-8.5)      |     | −1.1 (−8.9-6.7)        |     |
| More than 1 comorbidities                | 24 (20.7)    | 0.21 (−9.1-9.5)      |     | −0.0 (−8.7-8.7)        |     |
| Adverse effect of treatment              |              |                      |    |                        |    |
| No adverse effect                        | 79 (68.1)    | Reference            | 0.04| Reference              | 0.02|
| Gastritis                                | 23 (19.8)    | −11.2 (−20.1-2.4)    |     | −12.2 (−20.9--3.5)     |     |
| Others (neuropathy, recurring infection, itching, oedema) | 14 (12.1)    | −4 (−14.8-6.8)       |     | −5.0 (−15.5-5.5)       |     |

ISS, International Staging System
The difference in non-medical expenses for those living in Delhi versus those from outside Delhi was compared. The non-medical expenses were ₹1500 for non-Delhi residents compared to ₹200 for patients from Delhi. The median wage loss for those living in urban households was ₹1746.7 (IQR, ₹960-3000) and ₹300 (IQR, ₹200-500) for patients from rural areas (Table V). The median household expenditure by urban household was higher ₹13,480 (IQR, ₹5800-18,000) than rural household which was ₹9850 (IQR, ₹6500-16,850). Those patients who were on three-drug regimens had higher expenditure ₹13,160 (IQR, ₹8220-20,500) compared to those taking 2- or 1-drug regimen (Table VI). There was association between treatment regimen/supportive care ($P<0.05$) and household expenditure ($P<0.01$) with OOPE (Table VI). The treatment cost also varied. The expenditure for patients taking only supportive treatment as well as those on chemotherapy is mentioned in Table VII.

### Discussion

In the present study, the QoL and OOPE in myeloma patients were assessed during the various phases of treatment. The QoL scores in our study were higher than the respective reference values. The functioning scores were high suggesting better functioning of myeloma patients and bone pain being the most common symptom. The study also analysed OOPE and financial difficulties (part of QoL).

Patients’ characteristics were similar to those described in earlier studies. However, a few differences were observed, median age in our patients’ population was 59 yr, this was lower than those reported from North America (67-71 yr) and Europe. This possibly reflects population structure in India as almost 65 per cent of population is below 35 yr. Chang et al. have shown median comparable age from different countries; median age of 55 yr in India is comparable to 65 yr in the USA.

A higher proportion of patients had ISS stage III disease (61.3%) in the present study similar to earlier studies from India (45%) but was higher than those reported in studies from Europe (42%) and North America (17%). Compared to women, men were more affected, a finding similar to earlier studies.

In the present study, QoL mean score was 59.6, slightly higher compared to reference value of 55.7 in EORTC QLQ C-30 global health status/QoL score. This was similar to a study from south India (mean scores 55.3). Three European studies- one from France (mean score 57.8), Greece (mean score 62.6), and Denmark (mean score 61) have also reported similar results. A population-based study of Eindhoven Cancer Registry from Southern Netherland reported

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### Table V. Details of treatment cost

| Characteristics                                      | n=116 |
|------------------------------------------------------|-------|
| Wage loss per day of participant due to visit to OPD (in ₹) (n=35) |       |
| Urban (n=18)                                         | 1746.7 (960-3000) |
| Rural (n=17)                                         | 300 (200-500)   |
| Total wage loss for number of days while visited institute (in ₹) (n=35) |       |
| Urban                                                | 2265.7 (1600-3520) |
| Rural                                                | 500 (400-833.3)  |
| Current expenditure for myeloma treatment for 30 days (in ₹) |       |
| Medical expenses                                     | 7900 (4950-13,550) |
| Non-medical expenses                                 | 1150 (500-3100)  |
| Total household expenditure (in ₹)                   | 20,000 (2000-70,000) |
| Household type                                       |       |
| Urban                                                | 13,480 (5800-18,000) |
| Rural                                                | 9850 (6500-16,850) |
| Gender                                               |       |
| Male                                                 | 9900 (6000-16,140) |
| Female                                               | 14,000 (7500-22,000) |
| ISS staging                                          |       |
| I                                                    | 7805 (3000-16,000) |
| II                                                   | 11,500 (7500-19,700) |
| III                                                  | 11,200 (6300-17,200) |
| Treatment medication                                 |       |
| 3-drug regimens                                      | 13,160 (8220-20,500) |
| 2-drug regimens                                      | 11,600 (7100-18,000) |
| 1-drug regimen                                       | 7650 (4790-13,400) |
| No drug regimen (observation)                        | 5900 (1100-9650)  |

IQR, interquartile range; ISS, International Staging System

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France (mean score 57.8), Greece (mean score 62.6), and Denmark (mean score 61) have also reported similar results. A population-based study of Eindhoven Cancer Registry from Southern Netherland reported
mean QoL score of 55, while mean score was 63.3 in a patients’ self-reported study from Ireland. Difference in score in above studies could possibly be due to inclusion of patients in different phases of treatment. A significant proportion of patients in the present study were on maintenance phase after completing primary treatment and were likely to be symptom free or have minimal symptoms.

The present study showed higher mean score for emotional functioning (81.9) indicating that the patient was less tense, depressed, irritable and worried followed by cognitive functioning (78.9) which refers to patient having less difficulty in concentrating and remembering things. Similar findings were reported in studies from Denmark and the Netherlands. Other studies have shown higher cognitive functioning score followed by emotional functioning.

In the present study, the most common symptoms (score) were pain (39.8), fatigue (38.6) and dyspnoea (26.1). In a French study also, fatigue (49.3) was the most common symptom followed by pain (39.4) and dyspnoea (31.8). Similar observations have been reported in other studies.

Financial difficulties regarding treatment may vary from one healthcare system to another depending upon facilities and type of insurance available. While in most developed nations, health care is free or insurance covered, in low- and mid-income countries, health care is partially funded, some patients may get re-imbursement from the government or their employers, but largely patients and their families have to pool funds for the treatment. Thus, there is higher mean score in the present study for financial difficulties (29.3), compared to EORTC reference value of 16.6 which was expected. This was similar to a study from south India (28.6). In our study, 63.8 per cent of patients had financial difficulties, higher than that reported from Ireland (42%).

The disease-specific scoring by QLQ MY 20 data revealed disease symptom score of 27.87±25.1 and future perspective score of 78.2±25.7, indicating that patients were worried about dying and their health in the future. These observations were comparable to those reported in a study from south India (20.7±18.7 and 81±23, respectively). Unlike the present study, a multicentric study from the UK reported higher disease symptoms burden and lower future perspective (mean score 64.6) than our study; this study had included both newly diagnosed and relapsed/refractory cases of myeloma.

We also evaluated correlation between QLQ C 30 global health score and four domains of QLQ MY 20; there was a negative correlation between global health score and side effects (−0.53) and a positive correlation was seen in global health and future perspective which is 0.41, which was similar to result from a French study 0.46.

An effort was made to determine factors associated with global health status/QoL score. Myeloma stage (ISS III) and adverse effect of treatment were important predictors. These results were similar to a French study which showed adverse effect occurred in early phase of treatment and declined as treatment continued. Similar observations were made in a study by Robinson et al, showing QoL association with staging and performance status. Ramsenthaler et al did not find correlation between survival, ISS staging and treatment related variables with QoL.

In the present study, medicine cost comprised 61 per cent of total cost and expenditure towards investigations and transport was 12 and 19 per cent, respectively. These results were similar to a study among cancer patients where drug cost was 73.9 per cent and cost towards investigation and transport was 13.2 and 10.3 per cent, respectively. Another study from India conducted among cancer patients in few selected tertiary care hospitals of five different States showed that more than three-fourth of patients experienced financial burden which delayed their decision to treatment, 39 per cent borrowed money,
while in our study, the contribution made by own family and relatives was 57.7 per cent.

The major limitation of our study was that cost estimate made here was applicable to a public hospital, and these figures were likely to be different for patients being treated in corporate hospitals and those having insurance. There was a possibility of recall bias as details on cost were for the last 30 days and the medicines cost also included cost of medicine for comorbidities. The study did not consider caregiver perspective and their wage loss while accompanying patients.

In conclusion, our study suggests that measurement of QoL of MM patients on treatment should be done on a regular basis. It is a critical guide for a chronic disease such as MM management by treating physician and to create support system by family and friends. To deal with the problem of financial concern of poor families, there should be good referral system as well as provision of free diagnosis, low medicines cost and treatment cost and support of travel and lodging of poor patients.

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