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Unmet need in patients with multiple myeloma-a cross sectional study from India

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SUMMARY

Background: Unmet supportive care needs in multiple myeloma is an important but less well-studied problem. This study was conducted to assess the unmet needs of patients with multiple myeloma treated at a tertiary cancer centre in India.

Materials and Methods: This is a cross-sectional study done at a tertiary cancer centre in India. All patients diagnosed with Multiple myelomas who were on disease-modifying agents for more than a year and attended the OPD from 15th July 2015 to 30th July 2015 were included in the study. Informed consent was taken. CaSUN (Cancer Survivors Unmet Needs Measure) questionnaire was given to all the participants and a semi-structured interview was done by a trained rater.

Results: 63 patients (male=26, female=37) with median age 60 years (range 34 years to 80 years) participated in the study. 99.6% of the questions were attempted by the cohort (7 out of 1764 questions were unattempted). At least one unmet need was reported by 95% (60/63) of the patients. The mean number of unmet needs per patient was 7 (0-18). The five highest unmet needs reported by myeloma patients were "need to reduce stress in my life"-65%, "need to address concerns of cancer coming back"-56%, "need to handle social/work situations"-46%, "need for emotional support"-51% and "need to move on with my life"-51%.

Conclusion: Unmet needs in myeloma patients were significantly higher when compared to that reported in western studies (26.5%) and that in cancer patients in general (40%). This indicates an urgent need to improve the psychosocial and emotionally supportive care in myeloma patients in low and middle-income countries. More studies in a larger number of patients need to be conducted to accurately assess the unmet needs in this population.

Key words: unmet need, multiple myeloma, CaSUN, India

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INTRODUCTION

Cancer is a major public health problem worldwide with 18.1 million new cancer cases detected in 2018 as per GLOBOCAN estimates [1]. With advances in treatment leading to improved survival, providing optimal supportive care has become an essential part of comprehensive cancer care [2]. This supportive care need is not only related to physical aspects but also to psychological, social and spiritual aspects. Unmet need studies can capture the discrepancy between the care and services required to ensure the optimal well-being of the patients and what they receive in real. Apart from the health-related quality of life which has emerged as an important endpoint in oncology, the study of unmet care needs may help to bridge the deficiencies in oncological care [3]. Multiple evaluation tools have been used to measure unmet needs which vary widely in domains of measurement [4]. Commonly used tools include CaSUN (Cancer Survivor's Unmet Needs Measure) or SUNS (Survivor's unmet Need Survey) [5, 6]. CaSUN questionnaire was developed to identify the needs of patients 1-11 years post-diagnosis [7]. CaSUN questionnaire is a validated tool that fulfils the standards for acceptability, internal consistency and validity [7]. It consists of one open-ended question, 6 questions asking about positive changes and 35 questions on (met, partially met and unmet) needs. Also, there are tools like CaSPUN to assess the unmet needs of caregivers which is another important area [8].

Unmet need issues in haematological malignancies are less well studied compared to solid tumors though psychological morbidity is reported to be higher in these patients [9]. Multiple myeloma is one of the cancers where newer antimyeloma drugs resulted in significant improvement in survival [10]. Being an incurable disease with symptoms involving multiple systems, integration of supportive care with the novel agents is important in the treatment of myeloma. Though there are studies on health-related quality of life in patients with myeloma, those addressing the practical issues faced by the patients living with myeloma are scant, especially from a developing country. Identifying the unmet needs in this population can help to tailor the treatment to each patient and improve the overall outcomes. A study from the UK using CaSUN questionnaire to assess the unmet needs of myeloma patients and showed that one-quarter of the patients had unmet supportive care needs. In the same study another tool, CaSPUN, it was found that one-third of the partners had unmet

needs [11]. As it is clear that the unmet need in supportive care is a significant problem in developed countries, the magnitude of the same in a developing country may be manifold. But there is very limited information on the same from a low middle-income country. In this study, we describe the unmet needs of patients with myeloma on novel agents which are the first of its kind from India.

METHODS

This is a cross-sectional study done at a tertiary cancer center in South India. The study was initiated after obtaining approval from the institutional research board (IRB). All eligible patients who attended the OPD from 15th July 2015 to 30th July 2015 were included in the study. This included all patients diagnosed with multiple myeloma who were on disease-modifying agents for at least 1 year. Patients who were on treatment for a period of less than one year, those who were only on supportive care and those who are unwilling to participate in the study were excluded. Informed consent was taken. CaSUN (Cancer Survivors Unmet Needs Measure) questionnaire was given to all the participants and a semi-structured interview was done by a trained interviewer. In the questionnaire, we used there were 28 questions on 5 domains including existential survivorship, comprehensive cancer care, information, quality of life and relationships. Subjects can mark their response as i) whether there is a need or not ii) if there is the need, whether it is met iii) If there is an unmet need, how strong is the need (weak, moderate or strong). Also, sociodemographic parameters and disease and treatment characteristics were recorded.

Statistical methods

Statistical analysis was done using SPSS version 20. Means, standard deviations or medians (continuous variables) or frequencies and percentages (categorical variables) were calculated. Association between the level of unmet need and different factors were examined using chi-square analyses.

RESULTS

A total of 63 patients participated in the study. The median age was 60 years (34-80 years). Majority were females (n=37, 59%) and were from rural areas (n=58, 92%). Sixty-one patients (97%) were married. Most of the patients belonged to nuclear families (n=39, 62%) and the remaining 24 patients belonged to joint families. International Staging System Staging was available in 52 patients. The majority of the patients had ISS Stage III disease (n=24, 38%). Sixteen patients (25%) had stage I disease and the remaining 12 patients (19%) had Stage II disease. Fifty patients had bone pain (80%) which was the commonest symptom. Anemia was seen in 40 patients (65%) and renal dysfunction in 26 (41%) patients. The most common regime used was Melphalan/Prednisolone/Thalidomide followed by Lenalidomide/Dexamethasone, Cyclophosphamide/Bortezomib/Dexamethasone and Thalidomide/Dexamethasone. Three patients (5%) underwent autologous stem cell transplantation. Partial response or more was seen in 59 (94%) patients. The median duration from diagnosis was 23 months (12-92 months) (Table 1).

CaSUN

Of 1764 questions, 99.6% of the questions were attempted by the cohort leaving only 7 unattempted. At least one unmet need was expressed by the majority of patients (n=60, 95%). The five highest unmet needs reported by myeloma patients were "need to reduce stress in my life"- (65%) "Need to address concerns of cancer coming back" (56%), "need to handle social/work situations"- (46%), "need for emotional support"- (51%) and "need to move on with my life"- (51%). All these 5 needs come under the domain of 'Existential Survivorship'. Similarly, the top ten needs are represented with the strength of unmet needs in Figure 1. A mean number of unmet needs per patient was 7 (range 0-18). There was no significant difference in the level of unmet need between age groups (age<60 years Vs> 60 years), gender or area of residence (rural Vs. Urban).

Tab. 1. Baseline characteristics

Parameter	Number (%)
Median Age	60 (34-80 years)
Females	37 (59%)
ISS (n=52)*	
Stage 1	16 (25%)
Stage 2	12 (19%)
Stage 3	24 (38%)
Regimen	
MPT	25 (40%)
Lenalidomide/Dexamethasone	19 (30%)
Cy BORD	10 (16%)
Thalidomide/Dexamethasone	9 (5%)
Autologous Stem Cell Transplant	3 (5%)
Response	
No response	4 (6%)
PR	15 (25%)
VGPR or more	44 (69%)

*ISS staging was not available in 11 patients who were started on treatment from outside. PR: Partial Response; VGPR: Very Good PR; CyBORD: Cyclophosphamide, bortezomib, dexamethasone; MPT: Melphalan/Prednisolone/Thalidomide, ISS: International Staging System

Existential survivorship

This is the domain with a maximum number of unmet needs. The median number of unmet needs under domain was 4 (0-10). proportion of patients with unmet needs for factors under this domain ranged from 12% ("new relationships") to 65% ("reduce stress in life") and includes the top 5 needs. The strength of the need was mild to moderate for most of the patients. Among the 14 components under this domain, the majority of the patients had a need, but it was being met (30%-73%) (Table 2).

Other domains

In the domain of "Comprehensive Cancer Care "proportion of patients with unmet needs ranged from 2% ("managing with health team") to 29% ("complaints addressed"). In the domain of 'Information', this ranged from 6% ("need of an update information") to 23% ("need for understandable information"). Thirty-eight percent of patients were in need of "managing side effects" and 43% had the "need for change in the quality of life "(the domain of quality of life). Among the factors under the domain of relationships, the unmet need ranged from 9% ("problems with sex life") to 26% ("support from partner/family").

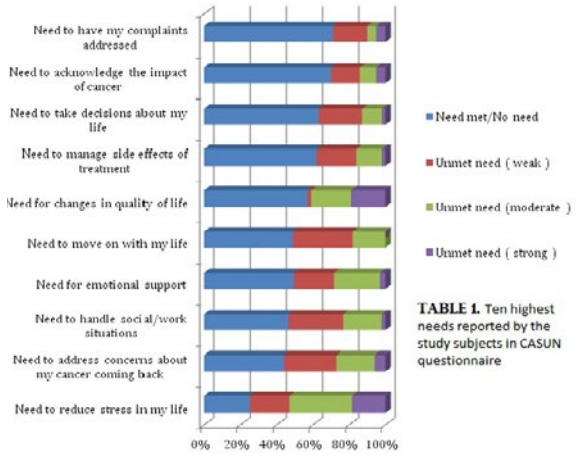

TABLE 1. Ten highest needs reported by the study subjects in CASUN questionnaire

Fig. 1. Most frequently reported unmet needs

DISCUSSION

Being an incurable disease with high symptomatic burden, understanding of unmet supportive care needs of patients living with myeloma is essential to improve the overall outcomes of this disorder. In this study, we highlight the unmet needs of patients with multiple myeloma who completed at least 1 year of treatment using CaSUN questionnaire which is a well-validated tool. Our study shows that myeloma patients in countries like India are having significantly higher unmet needs compared to the western population and the distribution of unmet needs is also different. This is one of the few studies reporting unmet needs of patients with myeloma living in low middle-income countries. Knowledge about these unmet needs will help to formulate strategies and allocate resources to improve the care and services of these patients.

About 95% of our patients had at least one unmet need which was much higher compared to that of a study from the UK [11]. Among our patients' majority belonged to rural areas and may be a factor contributing to the difference in the pattern of unmet needs [12]. But most of the needs were weak or moderate in both studies. Like other studies, the highest of the unmet needs belonged to the domain of existential survivorship [5]. The most common needs were related to reducing stress and the fear of cancer coming back. A systematic review of 17 studies reported that the fear of cancer recurrence, feeling uncertain about the future and reducing the stress were the top unmet needs of Australian cancer survivors [5]. But in the study from the UK, unmet need for accessibility to hospital car parking (40%) and obtaining insurance (39%) was higher than the fear of recurrence of cancer (30%) among patients who expressed a need [11]. In contrast in our patients, only 8% reported the unmet need for car parking whereas the other top unmet needs ranged from 46% to 65%. These findings again highlight the clear difference in unmet needs experienced by patients in developing and developed countries. Also, the unmet

Tab. 2. Distribution and strength of unmet need in the domain of existential survivorship

Sl no	Needs-based on Domains	No unmet needs		Need is currently unmet, How strong is the need?		
		No need or is not applicable	Have need, but the need is being met	Weak	Moderate	Strong
Factor 1 Existential Survivorship						
1	Reduce stress in my life	3 (5%)	19 (17%)	12 (19%)	19 (30%)	10 (16%)
2	Concerns about the cancer coming back	5 (8%)	23 (36%)	18 (29%)	13 (21%)	4 (6%)
3	Emotional support for me	1 (2%)	30 (47%)	14 (22%)	16 (25%)	2 (3%)
4	New relationships	23 (37%)	32 (51%)	5 (8%)	2 (3%)	1 (2%)
5	Talk to others	11 (17%)	36 (57%)	8 (13%)	8 (13%)	0 (0%)
6	Handle social/work situations	4 (6%)	25 (40%)	19 (30%)	13 (21%)	2 (3%)
7	Changes to my body	16 (25%)	36 (57%)	7 (11%)	3 (5%)	1 (2%)
8	Move on with my life	3 (5%)	28 (44%)	21 (33%)	11 (18%)	0 (0%)
9	Changes to beliefs	16 (25%)	40 (63%)	3 (5%)	2 (3%)	2 (3%)
10	Acknowledging the impact	9 (14%)	35 (56%)	10 (16%)	6 (10%)	3 (5%)
11	Survivor expectations	9 (14%)	43 (68%)	7 (11%)	4 (6%)	0 (0%)
12	Decisions about my life	13 (21%)	27 (43%)	15 (24%)	7 (11%)	1 (2%)
13	Spiritual beliefs	7 (11%)	46 (73%)	5 (8%)	3 (5%)	2 (3%)
14	Make my life count	15 (24%)	39 (62%)	3 (5%)	5 (8%)	1 (1%)

Tab. 3. Distribution and strength of unmet needs (domains other than existential survivorship)

Sl no	Needs-based on Domains	No unmet needs		Need Is currently unmet, How strong is the need?		
		No need or is not applicable	Have need, but the need is being met	Weak	Moderate	Strong
Domain 2 Comprehensive Cancer Care						
15	best medical care	3 (5%)	50 (80%)	5 (8%)	3 (5%)	2 (3%)
16	local health care services	3 (5%)	49 (78%)	7 (11%)	3 (5%)	1 (2%)
17	manage health with team	35 (55%)	27 (43%)	0 (0%)	0 (0%)	1 (2%)
18	doctors talk to each other	36 (57%)	24 (38%)	2 (3%)	0 (0%)	1 (2%)
19	complaints addressed	12 (19%)	33 (52%)	12 (19%)	3 (5%)	3 (5%)
20	accessible hospital parking	35 (56%)	23 (36%)	1 (2%)	2 (3%)	2 (3%)
Domain 3 Information						
21	up to date information	12 (19%)	47 (75%)	2 (3%)	1 (1.6%)	1 (1.6%)
22	information for others	2 (19%)	47 (75%)	0 (3%)	3 (5%)	1 (2%)
23	understandable information	5 (8%)	44 (70%)	5 (8%)	6 (10%)	3 (5%)
Domain 4 Quality of Life						
24	manage side effects	5 (8%)	34 (54%)	14 (22%)	9 (14%)	1 (2%)
25	changes to quality of life	2 (3%)	34 (54%)	1 (2%)	14 (22%)	12 (19%)
Domain 5 Relationships						
26	support partner/family	4 (6%)	43 (68%)	7 (11%)	3 (5%)	6 (10%)
27	impact on my relationship	9 (4%)	45 (71%)	4 (6%)	4 (6%)	1 (2%)
28	problems with sex life	31 (50%)	26 (40%)	4 (6%)	2 (3%)	0 (0%)

need for factors like "new relationships", changes to my body" and "changes to my belief" was less troubling for our patients. The difference in these unmet supportive care needs across high income and low middle-income countries was highlighted in a study done in cancer survivors in Asia pacific region [13].

Regarding factors under the domain of "comprehensive cancer care", the need was met for most of the patients. Unmet need 'for complaints addressed "was the highest unmet need in this domain with almost 1/3rd of the patients having the need. Lower unmet needs in this domain must be a reflection of the services provided by our centre which is an academic institution under the public sector in rural India. But in the domain of Information, 23% had an unmet need for "understandable information" indicating the need for comprehensive patient education. Also in the domain of quality of life, the unmet needs were relatively high with respect to "managing side effects" or "quality of life". The majority of the patients did not report "problems with sex life" or "impact on relationships" though about one-fifth had an unmet need for support from partner or family. This may be an underreported problem due to cultural barriers and the taboo associated with discussing problems related to sex in India (Table 3) [14]. We could not identify any factors predicting higher unmet needs among age, gender or area of residence. In a study in patients with haematological cancers, it was found that younger patients and those who are nearing completion of treatment had higher levels of unmet need [15]. Though our study had limitations in the form of a small number of patients and cross-sectional design it throws light on the unique issues faced by patients living with multiple myeloma in a low middle-income country.

CONCLUSION

Our study provides important information about the unmet supportive care needs of a patient living with myeloma in a low middle-income country. Our patients received novel agents for multiple myeloma and the majority of the patients had a good response to treatment. But they had very high unmet supportive care need with more than 90% having at least one unmet need. The highest burden of unmet need is in the domain of Existential survivorship warranting an integrative approach with the inclusion of psycho-oncology interventions. Larger studies are required to identify the magnitude of unmet supportive care needs and strategies to address this important aspect of myeloma treatment.

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