Clinical and Socio-demographic Profile of Hospice Admissions: Experience from New Delhi

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Abstract

Background: Our hospice caters to referrals from the wide areas in the northern Indian territory. A descriptive analysis of hospice admissions can bring to light, the status of palliative care in the region overall. **Aim:** The aim was to assess the clinical and demographic profile of hospice admissions in New Delhi during the time period 2016–2017. **Methods:** Hospice admission records from the calendar year 2016 were digitized from paper charts, and statistical analysis was carried out using SPSS v21. Patient and caregiver demographic profile and dominant referral and utilization patterns were retrospectively assessed. **Results:** One hundred and fifty-four admissions (mean age 51.8 ± 15 years; 60% females) were recorded. Up to one-third of the patients (48, 31%) were single at the time of admission. Majority of the patients had below 10th grade literacy level (116, 75.3%) and belonged to low socioeconomic status. Two large tertiary care centers were the most common referrers (54.6%). The top three diagnoses were head-and-neck cancers (56, 36.4%), gastrointestinal cancers (27, 17.5%), and metastatic breast cancer (23, 14.9%). Major patient-reported debilities were pain (73%), dysphagia (51%), and incontinence (45%). The mean duration from diagnosis to hospice referral was 2.7 ± 0.7 years. Majority of the patients (76%) reported to have undergone some form of oncologic treatment. Up to two-thirds of the patients received opioids with or without additional supportive care. **Conclusion:** Pain, dysphagia, and incontinence were the most common reasons for hospice referral, with incontinence being significantly correlated with the divorced status. There were no differences in the prevalence of other symptoms with relation to the marital status. Data on hospice utilization patterns in India are limited to pilot experiences. More data are needed to drive national-level policies.

Keywords: Dysphagia, hospice, incontinence, marital status, pain

INTRODUCTION

Hospice care in India is of emerging importance as progressive urbanization is linked to weakening of social support. India has a multicultural and multi-linguist population, totaling over a billion. This context drastically influences and complicates the palliative care needs and provision of palliative care in India. The vast population of India, its diversity, and sociocultural nuances highly limit generalization of palliative care research, which, in turn, constraints policy decisions at the national level. With enormous demand for palliative care and need for standardization of care, accelerated efforts at generating high-quality research data are paramount. After thorough literature search, one study in 1994 has been found which demonstrates the demography of the same hospice. However, no other studies especially in the context of Indian hospice were found to provide for a good comparison. A recent drift toward fragmentation of joint family in India is weakening the underlying social support. Both cross-sectional and prospective data collection of hospice admissions today can point us toward the recent trends, which can be highly instrumental in making policies for palliative care at the national level.

Community-based models, better known as neighborhood network model, have strong foothold in the southern states. On the other hand, majority of the palliative care provision in the northern Indian states rely on a few urban hospices that oversee multiple adjacent states. Great variation

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exists in staffing, care delivery, and overall vision between these hospices, and is largely governed by region-specific sociocultural norms and health-care attitudes. This paper aims to assess the demographic profile of annual admissions to a charity-run hospice. It is a subsidiary of the first-ever hospice established in India. This two-storied hospice with 36 beds and two physicians per shift, caters to only advanced cancer patients. Annual admissions usually range between 150 and 250 patients. Besides health-care personnel, trained nuns are a core staff who themselves reside within the hospice premises and help in all aspects of care including household chores. The hospice lives by its mission statement: "Where there is love, there is no pain." Through this descriptive analysis, we aim to uncover some of the logistic and sociocultural nuances of palliative provision in the northern Indian states. Further, we aim to compare these data with published data from both low- and high-income countries.

METHODS

After ethical approval, a retrospective review of prospectively maintained paper charts was conducted for patients admitted in between January 2016 and January 2017. Well-structured admission and discharge papers were available for all patients during this period. Minimal illegible and incompletely filled data were lost in the process of digitization. Collected variables included (i) patient demographics (age, sex, address, date of admission, and date of discharge); (ii) patient-specific factors (main symptoms, marital status, religion, education status, occupation, social class, and family structure); (iii) disease-related factors (duration since oncologic diagnosis, treatment received); (iv) caregiver-related factors (age and relationship with the patient); and (v) physician-related factors (type of referral center and timing of referral). "Caregiver" was the person who filled the dedicated section as a "guarantor" and helped with filling the majority of the admission form. Patients were divided into the following five classes based on employment status: professional (Class I), technical (Class II), skilled (Class III), semi-skilled (Class IV), and unskilled (Class V). Majority of the data were obtained from the patients at the time of admission. The form was completed within the first few days depending on the time availability and review of required documentation. Awareness of disease and awareness of prognosis were subjectively assessed, mostly directly from the patients. Data regarding death after discharge were not available and data regarding the hospice course were also not well documented. These two variables were omitted from the analysis. Data were analyzed using statistical software package SPSS v21 (IBM Corporation, Armonk, NY, USA). Male and female patients were compared to bring out gender-specific patterns. Both parametric (*t*-test, Chi-square) and nonparametric tests (Mann–Whitney *U*-test) were utilized for different variables. The factors that were found significant were assessed by multivariate analysis to assess the effect on days spent in the hospice [Figure 1].

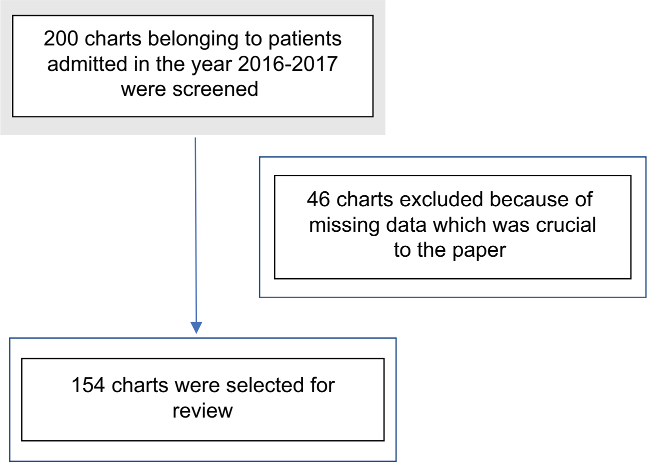

Figure 1: STROBE chart

RESULTS

Patient demographics

Age, sex, address, hospice stay, and death

One hundred and fifty-four patients were admitted in the study period. The mean age was 51.8 ± 15 years, with 60% (92/154) of them being females. Given the gender disparity between health-care utilization and important cultural gender-specific roles, gender-specific differences are separately tabulated in Table 1. In other words, 47% (73/154) of the patients were below 50 years.

Majority of the patients were from Delhi (66.8%, 101/154). Majority of them were referred from affiliated hospitals, AIIMS, and Safdarjung (56%, 88/154). Majority of the rest of the patients belong to adjacent northern Indian states of Uttar Pradesh, Haryana, Bihar, Rajasthan, and Uttarakhand in descending order. A handful of patients also came from far-away states such as West Bengal, Kashmir, and Kerala. When comparing patients from Delhi and from further away, a greater number of latter patients had malignant fungating wounds and were more educated. However, the corresponding findings tended toward but did not achieve statistical significance ($P = 0.07$ and $P = 0.61$, respectively).

The median hospice stay was 42 ± 12 days, with significantly longer stay seen for females ($P = 0.01$). While majority of the patients stayed between 30 and 60 days (60%, 93/154), about 20% stayed either less than 30 days out later than 60 days. Importantly, age ($P = 0.87$), type of analgesic use (opioid vs. nonopioid; $P = 0.51$), and marital status ($P = 0.76$) did not have significant influence on hospice stay. In addition, contrary to expected, patients who were from far did not stay longer ($P = 0.39$).

Information regarding the death date was available for 67% of patients, and majority of these were the ones that occurred in the hospice (79%; 81/103). In India, the patient with poor socio economic status have a better access to the hospice. This scenario is in contrast to western countries, no significant differences were found between the above-mentioned factors.

Table 1: Demographic characteristics

Category	Females (n=93), n (%)	Males (n=62), n (%)	P
Age			
<30	5 (5.4)	4 (6.4)	0.79
30- 50	47 (51.1)	16 (25.8)	0.002
50- 70	33 (35.9)	31 (50.0)	0.08
>70	8 (8.7)	11 (17.7)	0.09
Marital status			
Single	10 (10.9)	7 (11.3)	0.93
Married	63 (68.5)	43 (69.4)	0.90
Divorced/separated	19 (20.7)	12 (19.4)	0.84
Referred from			
Delhi and NCR	76 (82.6)	50 (80.6)	0.75
Other distant states	16 (17.4)	12 (19.4)	0.75
Hospital referring the patients			
AIIMS/Safadurjang	58	32	
Private hospitals	9 (9.8)	9 (12.9)	0.54
Government hospitals	23 (25)	21 (33.9)	0.32
Days spent			
30- 60	56 (60.9)	37 (59.7)	0.88
<30	14 (15.2)	19 (30.6)	0.02
>60	22 (23.9)	6 (9.7)	0.02
Religion			
Hindu	76 (82.6)	46 (74.2)	0.20
Others	16 (17.4)	16 (24.2)	0.30
Employment status			
Professional (Class I)	1 (1.1)	1 (1.6)	0.77
Technical/managerial (Class II)	16 (17.4)	21 (33.9)	0.02
Skilled (Class III)	0 (0)	3 (4.8)	0.03
Semi-skilled (Class IV)	6 (6.5)	15 (24.2)	0.002
Unskilled (Class V)	2 (2.2)	3 (4.8)	0.36
Unemployed	67 (72.8)	19 (30.6)	0.000
Accompanying relative			
Male	68 (73.9)	39 (62.9)	0.14
Female	20 (21.7)	22 (35.5)	0.08
Next of kin			
Son	30 (33.3)	17 (27.4)	0.25
Daughter	6 (6.7)	7 (11.3)	0.25
Spouse	31 (33.7)	17 (27.4)	0.41
In-laws	2 (2.2)	3 (4.8)	0.36
Parents	10 (10.9)	8 (12.9)	0.70
Relatives	3 (3.3)	5 (8.1)	0.18
Sibling	6 (6.5)	4 (6.5)	0.98
Diagnosis			
Brain	4 (4.3)	3 (4.8)	0.88
Breast	23 (25)	0	0.000
GI	15 (16.3)	12 (19.4)	0.62
GU	13 (14.1)	2 (3.2)	0.02
Nonsolid	2	2	
Head and neck	26 (28.3)	31 (50)	0.006
Lung	4 (4.3)	8 (12.9)	0.05
Musculoskeletal	1 (1.1)	1 (1.6)	0.77
Prostate	2 (2.2)	NA	
UK	0	1	
Median duration (year)			
Duration of diagnosis	2	1	0.79

Contd...

Table 1: Contd...

Category	Females (n=93), n (%)	Males (n=62), n (%)	P
NA	25	19	
Family structure			
Alone	17 (18.5)	12 (19.4)	0.89
Joint	3 (3.3)	2 (3.2)	0.99
Nuclear	72 (78.3)	48 (77.4)	0.90
Education			
Above 10th standard	25 (27.2)	13 (21.0)	0.38
Below 10th standard	67 (72.8)	49 (79)	0.38
Top three symptoms (not mutually exclusive)			
Pain	65 (70.7)	47 (75.9)	0.48
Dysphagia	48 (52.2)	30 (48.4)	0.64
Incontinence	49 (53.3)	21 (33.9)	0.02

NA: Not available, GI: Gastrointestinal, GU: Genitourinary, UK: Unknown, NCR: National Capital Region, AIIMS: All India Institute of Medical Sciences

Patient-specific factors

Patient-specific factors include awareness of diagnosis and prognosis, main symptoms, marital status, family structure, religion, education status, and occupation.

While all the patients were aware of their diagnosis at the time of admission, only two-thirds (77%, 118/154) had an accurate idea about their prognosis. Importantly, awareness of prognosis was not significantly different among cancer types. Although not statistically significant, among those unaware of their true prognosis, slightly greater percentage were males (62%), and it was unexpectedly no different between the educated and uneducated.

The three most common chief presenting symptoms [Figure 2] were pain (73%), dysphagia (51%), and incontinence (45%). The rest included nausea/vomiting (23%), malignant fungating wound (23%), altered mental status (22%), shortness of breath (21%), immobility (17%), bleeding (11%), and diarrhea and constipation (10%). As expected, females had higher rates of incontinence ($P = 0.02$). In patients who had received chemoradiation, chief symptom was vomiting ($P = 0.06$).

About one-thirds of the patients (31%, 48/154) were single, and among them nearly two-thirds were divorced/separated (31/48). Palliative care needs are vastly dependent on marital status, and this was consistently seen in our results [Table 2]. However, the most common symptom for referral was same in both married and unmarried groups. Incontinence was the only symptom which had a significant positive correlation with divorced status. Only 3.2% (5/154) of the patients lived in joint families. The rest either lived in a nuclear family structure (77.9%, 120/154) or lived alone (18.8%, 29/154).

Seventy-eight percent (120/154) belonged to Hindu religion [Figure 3]. Others included Muslim (11%), Christian (6%), Sikh (2.6%), Jain (0.6%), Buddhist (0.6%), and others (0.6%). Interestingly, greater proportion of patients from far were religious minorities (other than Hindu) ($P = 0.04$).

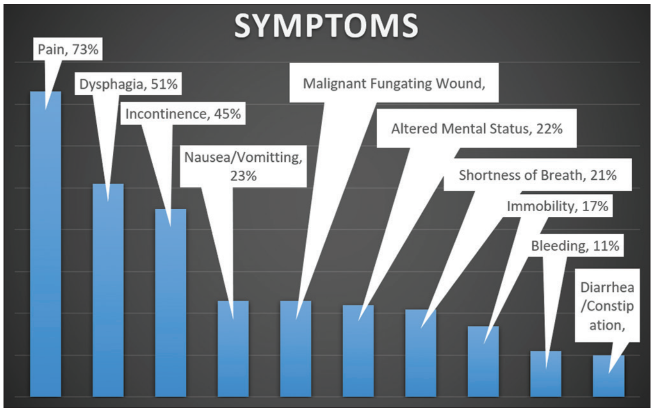

Figure 2: Symptom frequency in the patients at the time of admission

Two-thirds (75%, 116/154) of the patients were below 10th grade literacy level. Interestingly, although not statistically significant, slightly larger proportion of patients below 10th grade literacy, were males (males, 79%; females, 73%).

Just less than half of the patients were unemployed, with the patients being subclassified into the following six classes based on employment status [Figure 4]: professional (Class I), 3.2%; technical/managerial (Class II), 24%; skilled (Class III), 2%; semi-skilled (Class IV), 13.6%; unskilled (Class V), 3.2%; and unemployed (Class VI), 54%. Females constituted a significantly larger proportion among those unemployed (females, 72.8%; males, 30.6%, $P = 0.01$). Excluding the unemployed, technical/managerial and semi-skilled categories made up majority of the population, essentially pertaining to day-to-day labor jobs in most cases.

Disease- and treatment-related factors

The disease- and treatment-related factors include cancer type, duration since oncologic diagnosis, and treatment received.

The top three diagnoses were head-and-neck cancers (36.4%, 56/154), gastrointestinal (GI) cancers (17.58%, 27/154), and metastatic breast cancer (14.9%, 23/154). Other cancer diagnoses included genitourinary cancer, lung cancer, brain cancer, prostate cancer, hematologic cancers, musculoskeletal

Table 2: Association of symptom frequency with the marital status

Symptom	Single (*n*)	*P*	Divorced (*n*)	*P*	Married (*n*)	*P*
Pain	14	0.263	21	0.313	77	0.568
Dysphagia	9	0.523	16	0.532	53	0.474
Incontinence	10	0.180	6	0.001	54	0.031

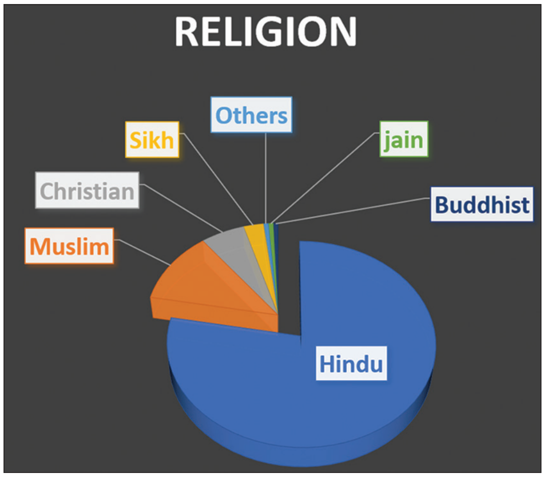

Figure 3: Religious characteristics of the patients during admission

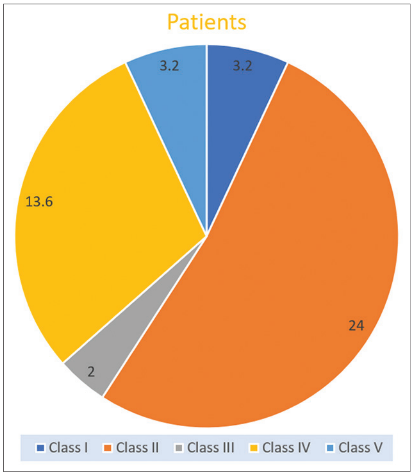

Figure 4: Class of the patients according to their employment status

cancers, and unknowns [Figure 5]. Patients with metastatic breast cancer tended to stay the longest followed by head-and-neck cancer, GI cancers, lung cancer, and others.

Patient who had received end-stage diagnosis within 1 year, 1 to 3 years, and >3 years were equally distributed (33.1%, 25.3%, and 20%, respectively). Nearly about one-third of the patients did not know at what point in their disease, were they diagnosed to be end stage (28.6%). Females tended to have longer duration of disease prior to admission ($P = 0.06$). Two-thirds of the patients had undergone some oncological treatment (chemotherapy, 69%; radiotherapy, 58%; surgery, 11%; single therapy, 29%; and combination therapy, 71%).

Two-thirds of the patients received opioids (66%) along with best supportive care during the hospice stay. Interestingly, as mentioned before, patients not receiving opioids stayed as long as patients who were on opioids ($P = 0.51$).

Caregiver-related factors

Majority of the caregivers were either children (39%) or spouses (31%). Parents (12%), siblings (6%), distant relatives (5%), and in-laws (3%) represented the rest of the spectrum [Figure 6]. Because a greater number of patients were females, expectedly, males exceeded females as caregivers [Figure 7]. In about 3% of the patients, information on caregivers was not available.

Although the spectrum of the chief presenting symptoms is reported above, it was interesting to see that a significant number of patients had malignant fungating wounds (23%, 35/154). This is expected to be an important factor, predisposing, especially the caregiver, to seek hospice admission.

Physician-related factors

Majority of the patients were physician-referred cases (exact percentage unknown), with a median duration since diagnosis averaging at 2.7 ± 0.7 years. Majority of the patients were referrals from the nearby tertiary care oncology centers, as mentioned above (AIIMS and Safdarjung, 58%). Among the patients referred from other nonaffiliated centers, 72% (44/61) of the referrals were from government/public hospitals and rest were from private hospitals [Figure 8].

Factors affecting days spent in hospice

Malignant fungating wound and shortness of breath were associated with longer days spent in the hospice with odds ratio of 2.310 (1.555–8.045) and 3.292 (1.149–4.644), respectively.

Discussion

The current study provides a bird's-eye view of annual admissions at a hospice in northern India, uncovering the underlying patient-related, referring physician-related, and disease-related factors that influence hospice admissions.

Although we compared our data with that of studies from South India evaluating patients enrolled in the neighborhood network palliative care model,[1] we were unable to find comparable data from other hospices from India. We also compared our data with that of large sample studies from one of the earliest palliative care establishments in the UK, from Sweden,[2] and from another larger study of hospice admissions from Singapore,[3] essentially as a surrogate of developed South-Eastern Asian country. Certain differences are worth noting.

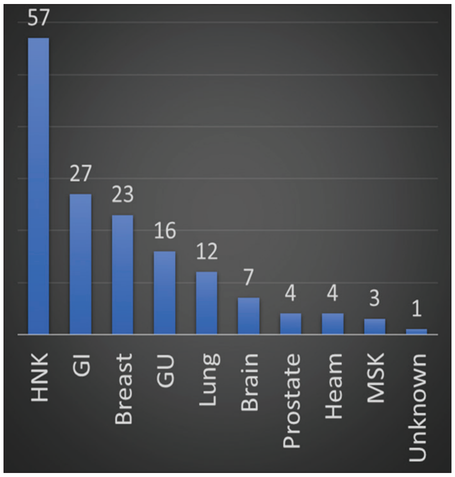

Figure 5: Frequency of diagnosis of the admitted patients

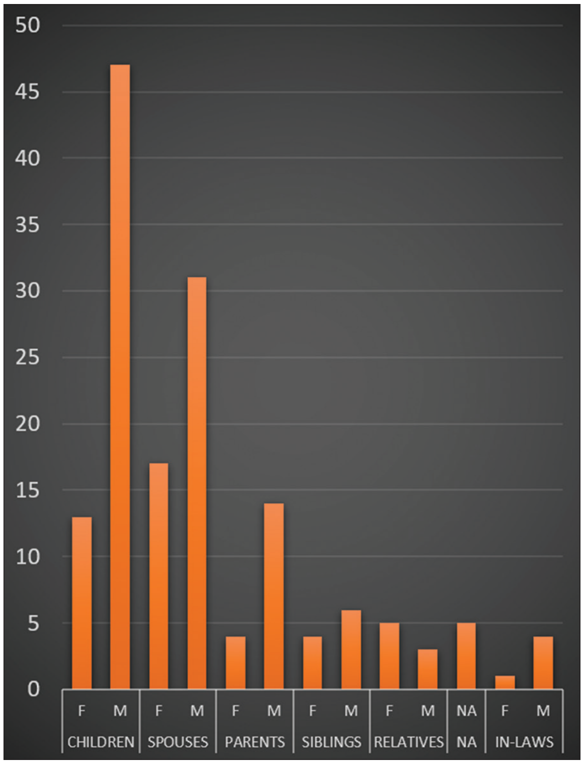

Figure 7: Gender of the caregivers

In our study, there were certain unique characteristics in the demography as compared to other studies. The mean age was younger as compared to that of studies from the Western countries.

In our study, the percentage of head-and-neck cancers was 37%, however 50% of the male population had a head-and-neck malignancy. The cancers with maximum length of stay were lung cancer and colorectal.

Back in 1994, after 6 years of establishing India's first hospice, Dr. L Dsouza published an article on the demography of 2000 patients who visited the hospice.[4] Fifty percent of the patients who were admitted had head-and-neck cancer. The

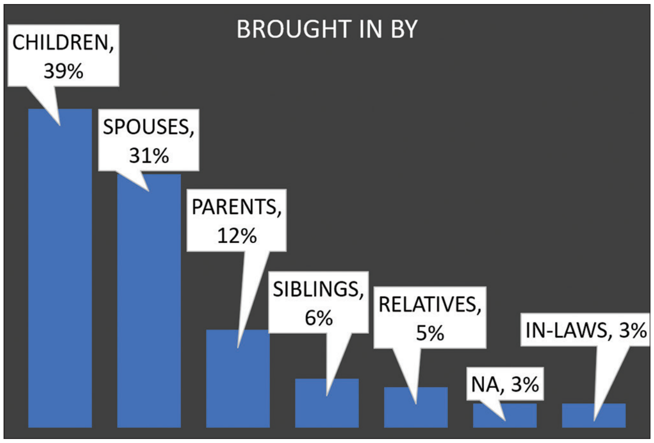

Figure 6: Relationship of the person who accompanied the patient for hospice admission

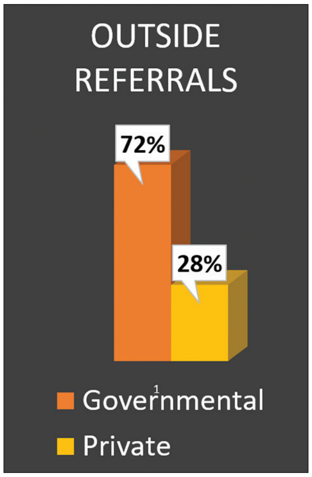

Figure 8: Main referral areas: public/government versus private

rest of the cases had gynecological malignancies. This brings to light an important similarity which persisted for a period of 23 years.

Malappuram district in Kerala (state in the southern part of India) is very well known for the establishment of a community-based palliative care project for 23 years now.[1] A study published recently described the demography of patients benefiting from the palliative care interventions in this district. The most important difference from our study, was that they had included all patients suffering from life-limiting and life-threatening illnesses apart from cancer. However, the patients with cancer formulated majority of their population (61%). There were almost equal females and males, with 14% of the patients above 80 years of age. This is an important difference from our study as we did not have any patient above the age of 80 years. The reason that may be cited could be the fact that palliative care was provided to the patient's home (community based) rather than through a hospice. Another important difference was in the caregiver's sex. Majority of the caregivers in our study were males, while in this study and other studies, they were females majorly.

In a study performed in Sweden, the demography of patients utilizing the hospice for the past 10 years was presented, by Karlsson *et al.*, in which the mean age of the admitted patients was 79 years.[2] Nearly 31% of the men were single and 59% were women were single. As compared to a wide difference in this study, there is an almost equal rate of single males and females in our study (10.9% females and 11.3% males). The age of the admitted patients was 27.2 years higher than that in our study. The head-and-neck cases were only 0.5% and 2.7% in females and males, respectively, which is contrast with the high rates in our study.

Another study examined the demography of a hospice in Singapore[3] in 1998, with the total admissions constituting 325. The most common cancers were lung, colorectal, and hepatobiliary cancer. This is in contrast with our study. The mean age was 64.7 years, which is 12 years higher than that in our population. This difference has been seen in other studies too.

Recent studies have put a lot of emphasis on the interaction of socioeconomic status with place of death.[5] In our study, we broadly divided the patients into the following five social classes: professional, technical, skilled, semi-skilled, and unskilled referring to the social Classes I–V, respectively. Sixty-six (42.8%) patients belonged to low socioeconomic status (unemployed and education level below 10th standard). Fifty-six (36.3%) patients were married and unemployed, only nine (5.8%) out of the unemployed patients were single, and 21 (13.6%) were divorced. Most of the unemployed patients were females. Thirty-one (20.1%) patients who were unemployed had more than 3 years of diagnosis.

There can be multiple reasons for the same; poorer patients in India have issues related to housing, for such patients a hospice is a respite. Being charity run, the hospice is equipped only to meet the basic needs of its patients. It would fall short of requirements/expectations of higher social classes in India, who prefer to take help of the home care team to care for their patient. In India, the patient with poor socio economic status have a better access to the hospice. This scenario is in contrast to western countries.

It was interesting to see in different studies, how the social class was related to the place of death. In a study by Kessler *et al.*,[6] 960 deaths were evaluated between the time period of 1999 and 2002. They realized that lesser number of patients from unskilled labors/social Class V had access to a hospice as compared to our study (6.9% of the patients from social Class V, died in the hospice). The reason cited was the passivity of the carers of that section of society to inquire about the hospice and also apparent societal pressure on the hospice for admissions.[6]

Another study by Taylor *et al.* on 890 patients in New Zealand, demonstrated that there were more acute hospital deaths as compared those at home, among patients with lower socioeconomic status.[7] Barclay *et al.* performed a study on 61,063 patients from the data obtained from 26 hospices and, after adjusting for age, sex, caregiver factors, etc., it was found that the odds of nonhome death decreased with decreased annual income. This implied more hospital death in those with lower income.[8] Chang *et al.* published a systematic review on the association of place of death with socioeconomic factors and reported that seven studies out of eight, did not find any correlation between financial status and place of death.[9] All the above-mentioned studies were from developed countries such as Japan, Spain, and Canada.[10-13] It, therefore, seems that the influence of socioeconomic status on the place of death may be unclear and different for developed countries as compared to that of developing countries. The poorer access of hospice to the patients with lower socioeconomic status is upsetting as admission to a hospice in the last days of life not only assures a "good death" but also reduces the cost of end-of-life care.[14]

Limitations

Besides the inherent drawbacks of a retrospective study design and small sample size, few other limitations are worth mentioning, namely (i) inclusion of a heterogeneous variety of diseases with preponderance of certain cancers which may skew the data; (ii) absence of data on emotional and psychological needs of both the patient and caregiver; (iii) presumptive assignment of caregiver status and limited demographic information about the caregiver; and (iv) limited data on family income, hospice course, choice of place of death, and exact information of death date.

CONCLUSION

This paper brings to light the social, clinical, and demographic profile of patients who visited the hospice in northern India. Majority of these patients had a late stage diagnoses, had undergone some form of oncologic treatments, and had little social or financial support. Pain, dysphagia, and incontinence were the most common reasons for hospice referral. These symptoms were not correlated with the marital status of the patient, except incontinence being significantly correlated with the divorced status. The similarity of most of the symptoms between these two groups highlights the helplessness/ineptitude of the spouses as caregivers, to deal with difficult symptoms at the end of life. Malignant fungating wounds appeared as an important determinant for seeking hospice care. When compared to Western literature, prominent difference in average age and social class was evident.

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Conflicts of interest

There are no conflicts of interest.

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