Impact of Home-Based Palliative Care Service on Symptom Burden of Patients and to Study the Caregivers' Satisfaction

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Summary

The specialised home-based palliative care services in case of advance cancer is help needed to relieve suffering from pain and other physical symptoms along with mitigation of psycho-social and spiritual issues of patients' and their care-givers. Our aim is to evaluate the effects of home-based palliative care services in terms of reduction in symptom burden of patients and to study reduction in emergency or hospital visit and to know caregivers' satisfaction. Total 350 patients were included in the study as stated in inclusion and exclusion criteria. The Edmonton Symptom Assessment Scale (ESAS) score was utilized to evaluate the patients' symptoms and care-givers' satisfaction was recorded using FAMCARE-2 Scales. We found significant improvement in physical symptoms after home based palliative care and during follow up. We found that more than 70% of the caregivers were satisfied with treatment, information and training regarding home care of patient. Only 75 (21.41%) patients need emergency visit or admission to hospital/hospice. 275 (78.57%) of advanced cancer were satisfactorily treated at home. We found 84% of patients died at home peacefully. So, we can conclude that Specialized home based palliative care can reduce readmissions to hospital by treating physical symptoms at home and increase care givers' satisfaction.

Keywords: Advanced cancer, Specialized home based palliative care, Physical symptoms, Caregiver

Introduction

The main purpose of palliative treatment is to intercept and alleviate suffering from pain and other physical and psycho-social issues and to come up with the finest possible quality of life (QOL) to patients and their care-giver, in spite of the advanced stage of disease.[1] There are different models of palliative service available in India including; inpatient care (in hospices or hospitals), outpatient clinics (in hospitals and other settings), and home care services (run by hospitals, hospices or volunteer networks).[1] The aim to provide specialized home-based palliative care services in case of advance cancer is to relieve suffering from pain and other physical symptoms along with in mitigation of psycho-social and spiritual issues of patients and their care-givers as much as possible.[1]

It is anticipated that incidence of cancer cases will surge to 12.8 per cent in 2025 compared to 2020.[2] It is commonly observed that majority of patients present in the advance stage of the disease. As a consequence, disease becomes incurable and only option left is the palliation.[2]

As we can manage pain and other physical manifestation and provide supports for psycho-social and other issues of patients and care-givers at home, Specialized home based palliative care is advantageous in case of advanced cancer patients. Other added benefits that home based palliative care provides are reduced hospital admission and emergency visit of patients, patients can be managed at home surrounded by their loved ones and also die peacefully with dignity at home.[1] Home based palliative care are well established in developed nations but in India there are few centres which provide specialized home based palliative care to advanced disease patients.[3-6]

As there are fewer centres which provide specialized palliative care in India, few studies or limited data are available regarding specialized home based palliative service and its effectiveness in Indian population. So, we designed this study at state cancer institute to know the effectiveness of specialized palliative treatment service at home to advanced cancer patients in reducing symptom burden and also to know satisfaction of their care-givers.

- Primary aim is to evaluate the effects of home-based palliative care services in terms of reduction in symptom burden of patients.

- Secondary aim is to study reduction in emergency or hospital visit and to know caregivers' satisfaction.

Material and Methods

This was a prospective cross sectional analytic study done from January 2023 to December 2023. Total 350 patients were taken up in our study as stated in inclusion and exclusion criteria.

Inclusion criteria

- Patients living within radius of 40 kilometres from the institute.
- Patients with advance malignancy
- Patients who fall into High Priority according to triage criteria of our department as shown in Table 1
- ECOG ≥3

Exclusion criteria

- Patients able to come to the hospital.
- Patients on curative treatment protocol

Home visit to provide home based palliative care to the selected patients according to inclusion and exclusion criteria were done by home visit team of Palliative Medicine department of our institute. Home visit team includes palliative medicine physician, palliative care nurses, counsellor, social workers etc.

During first visit our team did comprehensive assessment of patients and record symptoms on ESAS (Edmonton Symptoms Assessment Scale). According to patients' condition and symptom burden, treatment was given like pharmacological and non-pharmacological measures for physical symptoms, counselling and nursing care according to patients and care-givers' need. During next follow-up visit again symptom burden assessed by ESAS and care-givers' satisfaction were recorded using FAMCARE-2 Scales.[7] The FAMCARE-2 scale includes 17 components. The components relate to take measurement of satisfaction of the services given by palliative care teams with multidisciplinary focus. Each component has a five-point Likert scale that rate from very dissatisfied, dissatisfied, undecided, satisfied and very satisfied. In addition, the family members could select an additional option, "not relevant to my situation". The scale consists of four dimensions: 1) management of physical symptoms and comfort {five items}; 2) Provision of information {four items}; 3) Family support {four items}; and 4) Patient psychological care {four items}[(7)].

We collected demographic and clinical data like age and gender of patients, diagnosis and ECOG score. We recorded symptoms severity on ESAS scale on every visit and used data of first and second visit to know effectiveness of home based care. FAMCARE-2 scale was noted in follow-up visits. We also recorded number of hospital/emergency department visit of each patient.

Table 1: Triage criteria for home visit priority

Intensity of palliative care needs	Category for Home care visits
One symptom with score ≥ 7 Two symptoms score ≥5	High priority (HP) Every 3 - 7 days
One symptom with score ≥5, Symptoms responding yet not fully controlled after Palliative care intervention	Intermediate priority (IP) Once in 2 - 3 weeks
Adequate symptom control Stable palliative care needs	Low priority (LP) Once in 4 - 6 weeks

Statistical analysis

Continuous variable data were described as mean (X) ± standard deviation (SD), while categorical variable data were described as number (frequency) and percentages (%). Symptom burden on first and second visit was compared and p value (<0.05 is considered as significant) calculated by using t-test. Data of FAMCARE-2 scale were analysed in terms of frequency and percentage. For all this statistical analysis we used socscistatistics.com calculator.

Result

Total 350 patients were incorporated in our study. Mean age was 51 ± 13 years (range 8 to 93). We found that most common cancer was carcinoma of buccal mucosa followed by carcinoma of cervix in our study. Demographic & clinical data is shown in Table 2.

Patients and their families had comprehensive assessments at home. The ESAS score was utilized to evaluate the patients' symptoms. We found pain was the leading disturbing symptom among these patients with mean severity score of 6.3 ± 1.88 on first visit, followed by breathlessness, nausea/vomiting and depression with mean severity score of 4.7 ± 0.67, 5 ± 0.81 and 4.6 ± 1.64, respectively as shown in Table 3. We found significant improvement in severity of symptoms (P value <0.05) in follow up visit after home based palliative care. All these led to improvement in overall wellbeing of patients. There was no significant improvement in fatigue and appetite of patient.

We found that more than 70% of the caregivers satisfied with treatment, information and training regarding home care of patient by the home care services team during home visit as recorded by FAMCARE-2 scale. Description of detail of FAMCARE-2 scale is shown in Table 4.

Table 2: Demographic & Clinical data

Age (Years)(Mean ± SD)	51 ± 13
Gender (n; %)	
Male	202 (57.7%)
Female	148 (42.2%)
Diagnosis (n; %)	
Ca Buccal Mucosa	64 (18.28%)
Ca Cervix	58 (16.57%)
Ca Tongue and Lip	49 (14%)
Ca Breast	38 (10.85%)
Ca Lung	33 (9.4%)
Ca Prostate	25 (7.14%)
Ca Pancreas	23 (6.5%)
Hepatocellular carcinoma	21 (6%)
Bone Malignancy	15 (4.28%)
Ca Gall Bladder	12 (3.4%)
Others	12 (3.4%)
ECOG (n; %)	
0,1,2,	0 (0%)
3	206(58.85%)
4	144 (41.14%)

Table 3: Severity of symptoms according to ESAS

Symptoms	ESAS score (Mean ± SD)		P value
	Visit 1	Visit 2	
Pain	6.3 ± 1.88	2.9 ± 1.19	0.00014
Fatigue	3 ± 0.81	2.7 ± 0.67	0.3823
Nausea / Vomiting	5 ± 0.81	1.3 ± 0.67	0.00001
Depression	4.6 ± 1.64	1.5 ± 0.52	0.00002
Anxiety	3.7 ± 1.41	1.3 ± 0.94	0.00001
Drowsiness	2 ± 0.66	0.9 ± 0.73	0.0025
Breathlessness	4.7 ± 0.67	1.9 ± 0.73	0.00001
Appetite	3.3 ± 0.82	3.1 ± 0.73	0.5743
Sleep	3.2 ± 1.03	2.3 ± 0.82	0.044
Wellbeing	2 ± 0.81	1.2 ± 0.63	0.024

By providing specialized home based palliative care to these patients, only 75(21.41%) patients out of 350 needed emergency visit or admission to hospital/hospice. 275 (78.57%) of advanced cancer were satisfactorily treated at home, by home based palliative care as shown in Table 5.

As shown in Table 5, out of 21.14% patients, 16% of patients died in hospital / hospice that required

Table 4: Data of Caregivers' satisfaction (FAMCARE-2 Scale)[7]

Description	Satisfied; n (%)	Dissatisfied; n (%)	Not relevant to my situation; n (%)
The patients comfort	249 (71.14)	35 (10)	66 (18.85)
The way in which the patient's condition and likely progress have been explained by the Palliative care team	306 (87.42)	19 (5.42)	25 (7.14)
Information given about the side-effects of treatment	274 (78.28)	45 (12.85)	31 (8.85)
The way in which the palliative care tea, respects the patients dignity	244 (69.71)	40 (11.42)	66 (18.85)
Meetings with the palliative care team to discuss the patient's condition and plan of care	324 (92.57)	9 (2.57)	17 (4.85)
Speed with which symptoms are treated	257 (73.42)	29 (8.28)	64 (18.28)
Palliative care team's attention into the patient's description of symptoms	269 (76.85)	22 (6.28)	59 (16.85)
The way in which the patient's physical needs for comfort are met	309 (88.28)	10 (2.85)	31 (8.85)
Availability of the Palliative care team to the family	254 (72.57)	29 (8.28)	67 (19.14)
Emotional support provided to family members by the Palliative care team	294 (84.00)	12 (3.42)	44 (12.58)
The practical assistance provided by the palliative care team (e.g. bathing, home care, respite)	257 (73.42)	27 (7.72)	66 (18.86)
The doctors attention to the patient symptom	307 (87.72)	20 (5.72)	23 (6.58)
The way the family is included in treatment and care decisions	284 (81.15)	16 (4.58)	50 (14.28)
Information given about how to manage the patient symptom (e.g. pain, constipation)	255 (72.85)	46 (13.15)	49 (14.00)
How effectively the palliative care team manages the patient's symptom	302 (86.28)	19 (5.42)	29 (8.28)
The palliative care team's response to changes in patient's care needs	273 (78.00)	18 (5.15)	59 (16.85)
Emotional support provided to the patient by the palliative care team	266 (76.00)	28 (8.00)	56 (16.00)

Table 5: Details of emergency visits or admission to hospital/hospice; Place of death of patient

	Number of patients; n (%)
• Frequency of Emergency visit or admission to hospital / hospice	
None	275 (78.57)
1	47 (13.42)
2	18 (5.14)
More than 2	10 (2.85)
• Place of death of patient	
Home	294 (84.00)
Hospital	37 (10.60)
Hospice	19 (5.40)

admission or emergency visit to healthcare facility. Remaining 84% of patients expired at place of residence peacefully and with dignity.

Discussion

In Palliative care, by identification and early treatment of physical, psychosocial, and spiritual suffering we can improve the quality of life of patients suffering from life limiting illness and also that of their family. Palliative care is very much helpful in advanced cancer patients and their care givers because they are suffering from various physical, psycho-social and spiritual problems arise from disease itself and from its treatments.[8] Among various types of palliative care delivery models, home-based palliative treatment services increased the popularity of palliative care around the world.[8] Except in some areas in India major part of outpatients palliative care is restricted to hospital or clinical settings.[6] As there is great need of home based palliative care around our centre, we started providing home based palliative care for advanced cancer patients residing within radius of 40 kilometres from our institute. We did this observational study to find out its outcome.

We studied 350 patients; demographic data were comparable with other studies. According to Sathishkumar et al in their study of CANCER INCIDENCE ESTIMATES FOR 2022,[2] they found notable sites of cancer among males were lung, mouth, prostate, tongue and estimated predominant sites of cancer among females included breast, cervix and ovary. We found leading site of cancer in our patients was carcinoma of buccal mucosa, cervix, tongue, breast and lungs; which are similar to the above study.

We found significant improvement in physical symptoms like pain, nausea/vomiting, depression, anxiety, breathlessness and sleep during follow up of patients by providing specialist home based palliative care. But there was no significant improvement in fatigue and appetite. One study done by Kerr et al,[9] to see Clinical Impact of a Home-Based Palliative Care Program in New York found Six of eight symptom domains (anxiety, appetite, dyspnea, well-being, depression, and nausea) showed recovery while assessed with ESAS which is similar to our study findings. Robert B et al in their study titled 'Home Based Palliative Care: Known Benefits and Future Directions' also found the most widely described outcome is appropriate and acceptable control of physical and psychosocial symptoms such as pain, constipation, dyspnea, fatigue, anorexia, anxiety, and depression.[10]

By home based specialized palliative care, we can deliver extended support and enhance the skill of family care givers in caring their patients by providing necessary information and training regarding generalised nursing care, stoma care, feeding and medicine administration etc. and also providing psycho-social and spiritual care as needed.[11] Effectiveness of these can be measured by care-givers satisfaction. We did care-givers' satisfaction survey by using FAMCARE-2 scale and found more than 70% of the caregivers satisfied with treatment, information and training regarding home care of patient. Similar findings were found in studies done by Galatsch M et al for 'family care-givers satisfaction with home-based palliative care in Germany' and by Biswas et al titled 'Satisfaction with care provided by home-based palliative care service to the cancer patients in Dhaka City of Bangladesh: A cross-sectional study'.[7,8]

Various studies done in India and abroad found that by providing home-based palliative care to needy patients, we can significantly reduce patients visit to emergency department and admission to hospital in advanced disease and during end of life care.[1,9-11] So we can increase odds of patients dying at home. Patients with advanced disease dying at home exhibit better quality of life, physical comfort, and psychological well-being along with their care-givers than those dying in hospital setups.[9] In our study we found more than 75% patients were satisfactorily treated at home and did not require any hospital visit or admission. Only 21.41% patients needed hospital visits or admission with variable frequency and only 16% deaths had occurred in healthcare facilities. We found 84% of patients died at home peacefully. These findings are similar to the above mentioned studies in various parts of world.

Conclusion

From our study we can conclude that specialized home based palliative care can improve

quality of life, provide support to caregivers, reduce readmissions by treating physical symptoms at home and increase odds of 'death at home' of patients having advanced cancer.

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