



## ANALYSIS OF FACTORS ASSOCIATED WITH LOSS OF FOLLOW UP AFTER INITIAL CONSULTATION AMONG THE PATIENTS ATTENDING THE PALLIATIVE CARE CLINIC IN A TERTIARY CARE HOSPITAL OF RURAL AREA OF THE WESTERN INDIA-AN OBSERVATIONAL STUDY.

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### ABSTRACT

**Aim:** To determine factors responsible for loss of follow up and thereby to improve compliance and adherence to treatment in a palliative care unit.

**Methods:** Among the data of patients maintained in our department, we found 81 patients out of 1200 OPD visits who didn't turn up for follow up after the first outpatient department (O.P.D) visit in the study period [July 2017-June 2018]. After taking the institutional ethical committee approval we did telephonic interview of those patients and/or their relatives, took their consent to participate after explaining the study in brief. We noted the reason of not coming for follow up in our questionnaire. Out of 81, 61 patients could be contacted on phone.

**Results:** Major reason for loss of follow up was death after the first visit (n=31). 7 patients had started alternate medicine. Factors like exhaustion due to prolong treatment and difficulty in bringing patients were noted in 3 patients and 1 patient respectively. Other factors like lack of palliative care awareness, financial incapability, or no benefit from treatment were not found in any of the patient.

**Conclusion:** Death after the first visit was leading cause for loss of follow up. Majority of the deaths were within one month of the visit. Early referral and early palliative care interventions of those could have helped us to serve those patients better.

**KEYWORDS :** palliative care, hospice care, loss to follow up after first visit, loss of follow up

### INTRODUCTION

As per the WHO (World Health Organization) definition, palliative care is an integrated and holistic approach to improve the quality of life of the patients suffering from life-limiting or life-threatening diseases<sup>1</sup>. It deals with early detection of physical symptoms like pain and psychosocial, emotional and spiritual issues of the patients and caregivers. Specialist palliative care in the form of good team work with multidisciplinary approach helps in early identification of the patients for palliative care. The care when provided by regular follow up either in the form of palliative care OPD consultation, home visits or admission in hospice or palliative care unit serves the ultimate purpose of improved quality of life for such patients.<sup>2</sup> There are many barriers at multiple levels which prevent patients to reach to palliative care services on regular basis. To identify these factors is must for the efficient palliative care.<sup>4</sup>

In chronic illnesses where palliative care is recommended, patients are often exhausted with treatment part- physically, psychologically, socially and spiritually when they get referred to palliative care clinic. In our palliative care department, we come across patients who didn't turn up for follow up after the first outdoor patient services (O.P.D) consultation.

Follow up visits and treatment adherences are crucial for palliative care to achieve the ultimate goal of better quality of life of patients. So we decided to conduct this study to identify the factors responsible for loss of follow up especially factors relevant to our institute and surrounding locality which would help us to improve treatment compliance.

### Study Design And Methodology

In our palliative care clinic, on the very first consultation we explain the concept and need of palliative care and the services provided at our clinic to all the patients. We also maintain the data of all the patients visiting the clinic in the form of name, age, sex, address, diagnosis, date of diagnosis, treatment taken, date of visit to palliative care clinic, contact number, number of follow up visits etc. We designed a questionnaire based observational study to know the reasons for loss of follow up after the first visit. A list of patients who have had only a single visit to palliative care clinic over last one year [July 2017-June 2018] was obtained from this database. Among the data, we found 81 out of 1200 OPD (6.75%) visits who didn't turn up for follow up after the first consultation during study period. After taking the institutional ethical committee approval we did telephonic interview of those patients or their relatives. We had prepared a questionnaire for the probable factors responsible for loss to follow up based on literature review and expert opinion. We took their consent/permission to participate after explaining the study and its purpose in brief. We ensured privacy of the conversation. We were careful considering emotional aspects while talking to them over such sensitive issue. We noted the reason of not coming for follow up in our questionnaire.

### RESULTS

Out of 81, 61(75.3%) patients (Male: Female=36:25) (Cancer: Non-cancer=57:4) could be contacted on phone.

The factors identified for loss to follow up are summarized in table 2. As mentioned in the table, on analyzing the factors

affecting loss to follow up; we found that 31 out of 61 patients didn't turn up because of the death after the first visit which was almost 50% of the total. 7 patients had started alternate medicine in the form of ayurvedic or homeopathic medicines. 3 patients or relatives were exhausted with the treatment and only 1 had issue regarding bringing the patient to the hospital.

**Table No. 1 Demographic Data:**

Total No. of Patients (n=61)	Male( n=36)	Female (n=25)
Age(Mean±SD)	55.69±13.31	60.28±12.20
Diagnosis: cancer	33	24
Diagnosis: Non cancer illness	3	1
Residing in same district	29	19
From other districts	7	6

**Table No. 2- Results**

Death after the first visit	31 (50.8%)
Others	19 (31.1%)
Alternate medicine	7 (11.4%)
Exhausted with treatment	3 (4.9%)
Difficulty in bringing patients	1 (1.6%)
Not benefited	0 (0.0%)
No Palliative care awareness	0 (0.0%)
Financial	0 (0.0%)

The factors in others were comprised of shifting to other nearby hospital and ongoing treatment from oncology or radiation-oncology department. They were no patients who didn't turn up for follow up due to lack of palliative care awareness or financial issues or not getting benefited from palliative care clinic visit.

## DISCUSSION

The amount of time spent in palliative care department is significantly associated with the better quality of life in all domains for the patients compared to those who are not exposed to palliative care. Adnan Delibegovic et al studied lung cancer patients who got palliative care performed much better in physical, mental, emotional and social aspects at the end of two weeks compared those who didn't.<sup>3</sup>

Missing appointments in palliative care department are associated with overall symptoms burden and requirement of frequent admission in emergency care due to severity or worsening of symptoms, while frequent follow up helps in minimizing these effects.<sup>5,6</sup>

Samrat Dutta et al studied certain social or demographic factors which were among those which are not directly related to disease or patients and caregivers, still can impact the compliance and adherence to treatment.<sup>7</sup>

There are many barriers which prevent patients from reaching to palliative care services.<sup>4</sup> These barriers vary depending upon the place and surroundings where palliative care clinic is functioning.<sup>7</sup> It is necessary to determine these factors to overcome them to achieve the actual goals of palliative care. Usually financial or socio-demographic factors are expected to be significant for loss to follow up. Almost 50% (31 out of 61) patients didn't come after the first visit due to death related to terminal phase of illness. We also noted date of death of such patients. On analyzing the date of visit and date of death, we found that 15 out of 31 died within one week and 12 out of 31 died within one month of the palliative care clinic. Those were the patients who were actually referred very late in the terminal stage of illness to the palliative care clinic. Early referral could have given us and those patients more time for addressing various concerns and giving better quality of life and end of life situations.<sup>5,6</sup> Even with the good institutional support for referral to palliative care, referrals are often restricted to very terminal phase of life. Importance of early referral must be emphasized to primary treating physicians to

allow palliative care to intervene effectively. To our surprise, very few had financial or social concerns not allowing them to do frequent visits, which were expected to be more significant. Sometimes it is possible that relatives hesitate or feel guilty to express these concerns due to their limitations. 7 patients out of 61 were taking alternate medicine and left taking conventional care. Such patients can be explained to continue palliative care along with ongoing alternate medicine to minimize symptom burden. It was satisfying for us that all were aware about the concept of palliative care. Explaining about palliative care in detail on the very first visit helped us to prevent this factor becoming a barrier.

## CONCLUSION

For our institution, we found major factor responsible for loss of follow after the first consultation was death of the patients within one month of their visit or referral. Early palliative care referral should be emphasized to primary treating physicians to improve the palliative care outcome in needy patients.

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