

Original Article

NEEDS OF TERMINALLY ILL PATIENTS AND THEIR FAMILIES: AN EXPERIENCE WITH FIFTY THREE PATIENTS ATTENDING A NEWLY ORGANIZED PALLIATIVE CARE SERVICE IN BANGLADESH

Nezamuddin Ahmad, Mustafa Kamal, AHM Mostak Anwar, AKM Shafiqur Rahman

ABSTRACT:

Objective. To identify the needed care of the terminally ill patients and their families in Bangladesh

Design. Retrospective, descriptive cross-sectional study

Setting. Out Patient Consultation, referred admitted patients and home care visits by the same palliative care team of Bangabandhu Sheikh Mujib Medical University (BSMMU)

Participants. 53 terminally ill cancer patients registered with the palliative care service of BSMMU

Results. Age range of 22 to 80 years, mostly from middle to poor class. Most of the patients needed relief from pain, anxiety, sleeplessness and constipation along with other symptom relief. Major concern of patients was financial whereas major concern of family members was not to inform the patient of the disease status.. Preferred site of care was at home when uncertainty about the disease status was reduced.

Conclusion. even if a 'good life' is not possible for all the people of Bangladesh, 'a good death for most of the patients suffering from incurable diseases can be an affordable reality.

Key words: need, symptom assessment, palliative care, Bangladesh

BACKGROUND:

Palliative Care (PC) attempts to relieve suffering and improve the Quality Of Life (QOL) of the living and the dying¹. PC has been defined by the World Health Organization (WHO) as 'the active total care of patients whose disease is not responsive to curative treatment'. In addition, WHO stated that

"the control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount". PC affirms life, regards dying as a normal process; neither hastens nor postpones death, supports the patient and the family in living actively, and supports the family during the dying process of their family members and in bereavement². This emphasis recognizes that most of the cancers in the developing world are incurable at diagnosis, if they are diagnosed at all³. Due to the predominantly cure based approach of modern medical science, more than 30 million people suffer unnecessarily from severe pain and other symptoms each year in the world⁴. Having recognized this, a balanced view also acknowledge that in last sixty years enough knowledge has been gained in medical science to relieve much of these sufferings in a very affordable way and thereby enabling a person's peaceful exit from life.

It has been shown that physical symptoms of patients in terminal phase of disease are associated with increased distress⁵ as well as major depression⁶ and anxiety⁷. Distress is, in turn, influenced by diverse psychosocial and cultural factors. The assessment of symptoms and symptom distress is, therefore, a vital aspect of clinical care, particularly in advanced and incurable illnesses for which the primary goals of care may relate to comfort and quality of life (QOL)⁸. The prevalence of symptoms contribute to determining the patient's needs in terms of symptom control and therefore provision of services. Measuring symptom changes over time is used to assess whether treatments are effective. In education, clinical staff needs to know how often they are likely to encounter a symptom and what its likely causes are⁹. Symptom epidemiological data can help to direct assessments of health care need, for planning service, and to indicate how many

services are needed. Further, symptom measurement information can direct research and audit ¹⁰.

Methodology: The study presents a total Fifty nine patients who were referred to the Palliative Care Service (PCS) of Bangabandhu Sheikh Mujib Medical University (BSMMU) by physicians of different disciplines. The PC unit is recently formed one in the country. The time period during the study was from November 2007 to May 2008. Six patients were non-cancerous complaining of symptoms from other origins and were excluded from the study. This was a retrospective cross-sectional descriptive study. Out of Fifty three patients, forty visited the out patient consultation service where as 8 patients were admitted in other units and PC consultation was sought by the respective departments. Five patients could not come to the hospital and the team went to see them at home. Relevant data were collected from the record sheets which was prepared (with some modification) following the ones used by the Institute of Palliative Medicine, (IPM), Calicut, Kerala. All efforts were given to get the maximum information during the first visit of the patients. The data sheets were completed exclusively by those doctors and nurses who successfully completed their Basic Certificate Course in IPM and now run the unit.

Results: Out of these fifty three patients, 25 were females (47.16%); where as 28 (52.83%) were male. The age of these patients ranged from 22 to 80 years with an average of 53 years. All these 53 diagnosed cases of cancers had undergone radiotherapy and /or Chemotherapy and 24 patients had undergone surgery prior to the referral. All these patients were considered to have reached in an incurable phase of the disease by their treating physicians during the referral. Socioeconomic status of these patients were categorized as 3 (5.66%) very poor, 15(28.30%) poor, 23(43.39 %) middle class, 10 (20.75%) belonged to the affluent group. These 53 patients had a total of 246 members in their families directly living with them. 39(73.58%) patients were the only earning members of their family.

27 (50.94%) patients came from Dhaka city whereas 26 (49%) came from outside Dhaka city. Out of the 26 from outside Dhaka, 4(15.38%) had their family attendants staying in hotels, 10(38.46%) had been

staying with some of their relatives living in Dhaka and attendants of 12 (46.15%) patients had to stay in the hospital ward, sharing the patients' bed. The duration between the diagnosis of the disease and first consultation by the PCT was minimum 1 month to a maximum 96 months with an average of 11 months.

On the first visit, the number of complaints by the patients varied from minimum 3 to maximum 16 symptoms with an average of 7. The most frequent symptoms were pain 47(88.6%), insomnia 29(54.71%) anxiety 27 (50.94%), loss of appetite 22 (41.50%) and constipation 18(33.96%). 4 of the patients had malodorous disfiguring ulcer and 5 had colostomy done. 3 had features of chronic intestinal obstruction before death. Detail psychological assessment could not be done properly due to lack of expertise and experiences. Total number of contact for any single patient or his/ her attendants was from a single to 24 visits. Most of the telephonic contacts were not recorded. 11(20.75%) patients could not be traced later. Loss of contact with the patients happened from after one day to even after 118 days. An enquiry was made to assess how much the patient knew about his/ her diagnosis, perception and prognosis of the disease, 38 patients seemed too had known that they had cancer or that the disease was incurable. However, the exact level of their perception could not be detected due to a number of factors including the family members concern. All the accompanying family members knew about the incurable state of the disease. 47 attendant during the first visit thought that their patients did not know about the diagnosis or prognosis of the disease. None of the family members were willing to inform the exact diagnosis or prognosis of the disease to the patient during the first visit. One of the major concerns to the patients were financial issues like repaying loan, arranging treatment expenses and other living expenses of their dependents.

Follow-up records show that 13 deaths took place in the hospital whereas rest of the 29 occurred at their homes. The family members informed death to the PCT within a minimum of one hour to a maximum of seven days, mostly within twenty four hours.

Table –I
Demographic data.

| | | |
|------------------------|--------------------------------|---|
| Total number : (n= 53) | Primary diagnosis : | Some observations : |
| Male: 25 | Breast 5 | No of contact with single patients: Single to 24 visits |
| Female: 28 | Oral cavity 4 | Major concern of the patients : financial issue |
| Age range 22-80 yrs | Gall bladder 3 | Major concern of family : Not to inform the diagnosis/ prognosis to the patient |
| Average 53 yrs | Rectum 6 | Place of death : 13 in hospital, 29 at home |
| Socio-economic status | Pancreases 4 | Earliest time PC team is informed of death : < less than an hour |
| Very poor 3 | Lymphoid organs 4 | |
| Poor 15 | Urinary bladder 3 | |
| Middle class 23 | Colon 3 | |
| Affluent class 10 | Prostate 1 | |
| Common symptoms: | Esophagus 3 | |
| Pain –47 | Bone 2 | |
| Sleeplessness-29 | Lung 4 | |
| Anxiety-27 | Kidney 2, | |
| Loss of appetite-22 | Others 8(Primary not detected) | |
| Constipation-18 | | |

Table II
Results from two multi-centre analyses done abroad of symptom prevalence of patients with progressive illness.⁹

| Study, Population no and type of Sites, no of patients, & conditions if given | How symptoms are assessed | Prevalence of common symptoms |
|---|--|---|
| Kutner et al 2001 16 hospices n =348; 55% cancer (14 % cardiac failure, 12 % neurological, 11% respiratory, 16% others. | Memorial Symptom Assessment Scale(staff assessed) recorded in cross sectional sample of patients in care of hospice teams | Lack of energy,83% ; pain ,76% ; lack of appetite , 63%; feeling drowsy,61%; sad, 51%; short of breath,48%; agitation,48%;worrying, 43%; cough, 42%; nervous, 42%; constipation, 39%; irritability, 38%; swelling of arms and legs, 36%; difficulty sleeping, 35%; weight loss, 35%; dry mouth, 34%(plus 16 other symptoms with prevalence ranging 3-30). |
| Vainio et al 19967 hospices or palliative care services, n =1840, all cancer | Range of standardized and non-standardized measures, only 8 symptoms recorded assessed at referral to the units, in some instances by staffs and sometimes by patients | Pain, 57%; weakness, 51%; weightloss, 39%; anorexia, 30% ;constipation, 23%; nausea, 21%; dyspnoea, 19%; insomnia, 9%; confusion, 8% |

Table-III
Symptoms associated with Terminal Cancer, a comparative meta analysis⁵

| Symptom | Addington –Hall et al (1992) (N=203) | Vachnon et al Coyle et al (1989) (N=90) | Vachon and Fitch (1989, 1990, 1991) (N=69) | (1993) (N = 23) |
|---|--|---|---|---|
| In pain | 55% -56% | 100% | 80 – 100% | 88% |
| Decreased energy/ Weakness/tiredness/fatigue | 43% | 67 -94% | 70% | |
| Appetite disturbances | 58% | 62 – 71% | 61% | |
| Psychological distress | 49 – 54% | 47 – 67% | 52 % | |
| | 50 – 56% | 21% anxiety | 29 – 71% | 61% |
| | Depression | feelings of Depression, anxiety Frustration | feelings of Depression, anxiety Frustration | |
| | 32% - 43% Anxiety | 20% Suicidal Ideation plus 4% Suicidal intent | 61% -79% high distress on 30 item GHQ | 83% high distress on 30 items GHQ |
| Breathing problems | 61% | 17% | 35% -47% | 26% |
| Nausea | 19%-20% | 12% | 16% -49% | 43% |
| Difficulty to walk/climb stairs | 18% | 54% -74% | 48% | |
| Sleep disturbance | 35% - 37% | 24% | 40% -54% | 43% |
| Constipation | 31-36% | 30%- 42% | 35% | |
| Confusion/ concentration | 24% | 27% -38% | 43% | |

DISCUSSION:

The symptoms of persons in the terminal phase of illness have been documented in a number of studies from different countries^{5, 6, 8,9,10}. These studies show that the terminal phase of disease is associated with increased physical as well as significant psychological disturbances. Table I shows some the findings of the study done locally whereas Table II and III show a comparison of some of these studies indicating clinically challenging physical problems, poorly controlled symptoms and psychological dysfunction. These studies also noted that symptoms reported were limited to those mentioned by patients, and an assessment of particular symptoms was not made. Clearly the major symptoms reported in all these studies were similar, although the frequency of symptoms varied fairly widely. The differences presumably reflected both diagnostics differences as well as the efficacy of treatment.

In this study an almost equal proportion of male and females, probably implies that the need of comfort care is equally appreciated for both the groups by their family members. Another finding in this defined population shows that all the patients had been undergoing chemotherapy, radiotherapy and a significant number had surgery, a futile curative approach till the very end of the disease without really attending the comfort issues. This finding correlates very well with studies done elsewhere showing increasing trends in the aggressiveness of cancer care by chemotherapy and /or radiotherapy till the very end of life¹¹. This study also shows that in progressive illness symptoms are common and multiple. At the same time, the studies show a wide variation in the reported prevalence of even very common symptoms in cancer. Variation in the design of prevalence studies, difficulties in assessing the presence or absence of the symptoms and difficulties in defining the type of symptoms are three important reasons of this wide variation.

For example, the prevalence of pain, probably the most common symptom varies greatly between different studies even in cancer^{9, 10}. This study showing an 88% prevalence of the unnecessary sufferings of pain. But it needs to be appreciated that for proper understanding and management, pain has to be defined accurately. It may be chronic, or acute, or a combination of both, may have different patho- physiologies e.g. naturopathic or nociceptive. Pain may also have different causes, either as a direct or an indirect result of the main illness, as a side-effect of treatment, or due to another cause entirely. Depression, other quite common symptoms in some studies but has not been included in this one. It has been acknowledged that depression may be difficult to detect, professionals may fail to detect it and patients may not wish or be able to acknowledge its presence⁶. Fatigue, although now accepted as very common in progressive illness, has a long history of being overlooked because it was seen as inevitable, and professional did not ask about it and patients did volunteer information about it.

In this study attempt has been taken to look into the psychosocial and family of aspects of care. Only 20 percent of the patients belonging to the well-off group by local standard were referred to the PC service of this tertiary centre. Rest of the patients was from lower to middle class group. It needs to be further evaluated in future if homogeneity really prevails in providing PC to the community. A very pertinent finding of another local survey of 7516 new cancer patients attending the out patient consultation in 2005 reveals that more than 80% of patients were earning less than Taka 5000/ per month¹².

Most valuable observation in this study probably is the acceptance of the PC team members by the families as revealed by expressing the issues of concerns, informing the death of the patients to the PC members immediately and quite often seeking bereavement support. This is not a very usual phenomenon in this country. The team believes that clear, consistent and empathic communication with the patient and family about the natural history of the cancer and its prognosis is at the core of an effective palliative care.

More work is needed, particularly keeping in mind the different socio-economic background and family

concept of developing countries to systematically examine the relationship between normal developmental milestones of families as they encounter the cancer illness experience in the family. There is strong evidence in different literatures that family members' experience considerable stress when a member is diagnosed with cancer and may even have higher level of anxiety than the patients themselves. Concerns of family's center around worries about the patients comforts emotional intensity of losing the patient and need for honest accurate information. Families may be willing to play a more active role in care decision at this stage. Family members may use different coping strategies which should be appreciated by the PC team without being judgmental. Responses to cancer illness have also been described in terms of physical and psychological health changes of family members both during the illness and in the bereavement period. A number of studies related the importance of health care providers behaviors aimed at providing high quality physical care to the cancer patients.

RECOMMENDATIONS:

Future studies are needed to compare the symptoms of similar samples of those terminally ill who are receiving palliative treatment in a variety of settings and to measure the effectiveness of the interventions strategies used. As the palliative care movement grows in this country, it has to develop into an integral part of, rather than the antithesis of comprehensive cancer care. Primary treating team can provide most of the care needed by the patients. Intractable symptoms or complex psychosocial problems can benefit from the inclusion of palliative care experts. As the disease progresses and the prognosis becomes a matter of time, collaboration with palliative care team is usually advised to best meet the many needs of the patients and the family. Palliative care can be provided using limited resources with minimal infrastructure support¹³.

REFERENCES:

1. Stjernsward J, Batiste X G. Palliative Medicine—The Global Perspective: Closing the Know-Do Gap. In Oxford Textbook of Palliative Medicine, 3rd Ed. New York: Oxford University Press, 2004.
2. Sanchia A. Global perspectives on palliative care. *Cancer Nursing*, 22(1):33-39, 1999.

3. Rajagopal M.R, David Mazza and Arthur G. Lipman. Pain and Palliative Care in the Developing World and Marginalized Populations: A Global Challenge. *Journal of Pain and Palliative Care Pharmacotherapy*. 17 (3/4) 2003.
4. Stjernsward J, Folley K M, Ferris FD. The Public Health Strategy for Palliative Care. *Journal of Pain and Symptom Management*. 33 (5) 2007.
5. Vachon Mary L. S, Kristjanson L, Higginson I. Psychosocial Issues in Palliative Care: The Patient, the Family and the Process and Outcome of Care. *Journal of Pain and Symptom Management*. 10 (2)1995.
6. Houts PS, Yasko JM, Harvey et al. Unmet needs of persons with cancer in Pennsylvania during the period of terminal care. *Cancer* 62 (1) 1988.
7. The prevalence of psychiatric disorders among cancer patients *JAMA* 1983,249.
8. Cassileth BR, Lusk EJ, Walsh WP Anxiety levels in patients with malignant disease. *Hospice J* 2 1986.
9. Ingham J M, Porteonoy RK. Patient Evaluation and Outcome measures, The measurement of pain and other symptoms in *Oxford Textbook of Palliative Medicine*. Doyle Derek, Hanks Geoffrey, Cherny Nathan and Calman Kenneth. Third Edition, New York: Oxford University Press 2007.
10. Maclllmurray M. Symptom management in *Oxford Textbook of Palliative Medicine*. Doyle Derek, Hanks Geoffrey, Cherny Nathan and Calman Kenneth. Third Edition, New York: Oxford University Press 2007.
11. Hospital Cancer Registry, National Institute of Cancer Research & Hospital, annual report 2005.
12. Palliative Care. NCCN Clinical Practice Guidelines in Oncology. V.I.2007, www.nccn.org
13. Clemens K E, Kumar S, Bruera E , Klaschik E, Birgit J Lima L. Palliative Care in developing countries: what are the important issues? *Palliative Medicine* 2007; 21:173-175.