MODEL OF HOLISTIC CARE IN HOSPICE SET UP IN INDIA

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"DYING AND TERMINALLY ILL ARE NOT SEPARATE KIND OF PERSONS"

I INTRODUCTION

In a developing country like India, with population of over one billion, with 75% of rural population, most people die quickly of infection and injuries. High maternal and infant mortality rates across the country leave very less scope for the community to empathize with 'people having chronic illness and painful cancer.' They are generally considered by the health professionals as 'hopeless cases' and relative's categorise them as 'a gone case' or 'lost investment'.

It is only a decade and half since issues like **'Care at the End of Life'** and **'Respite Care'** is growing as major concerns for the health professionals in India. **India's first Hospice,** with modest beginning and now 50 bedded, was started in 1986 at Bombay as SHANTI AVEDNA ASHRAM for palliative care/ continuing care to patients with advanced and terminal cancer. These patients who are totally shattered medically, physically, emotionally, economically and spiritually, receive this care free of cost, irrespective of their age and economic status. By now, there are nearly 10 Hospices in India with bed strength of 20 to 50, managed by religious groups and private sector.

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II THE CONCEPT OF HOSPICE

Hospice care is a unique concept of care that provides comfort and support to people and families dealing with life limiting illnesses. The aim is to provide expert pain and symptom management, combined with compassionate care, to allow patients live each day to the fullest, in their home or homelike setting such as assisted living facilities, Hospice or Ashram.

III HOSPICE IN INDIA

The term Hospice was once described as a place of shelter and rest for weary travellers on a long journey. Hospice was first applied to a specialized care for people at the end of life in 1967 at St. Christopher Hospice in London and as Shanti Avedna Ashram in India (Bombay) in 1986. **SHANTI** means peace, **AVEDNA** means absence of pain and **ASHRAM** is a place of rest, a home.

Today palliative care is provided through an inter-disciplinary team, with the principle of **"Quality of life at the end of life."**

IV PHYSICAL SET UP OF HOSPICE / ASHRAM

The Ashram is located near two big hospitals on the main road. It has a reception and a common prayer room. The Nurses station and patient's beds are placed in circular form. There are two side rooms for very serious patients. And those in their deathbeds are shifted to these rooms, two treatment rooms and a kitchen cum pantry are also available.

V OPINNIONIARE FROM THE NURSE ADMINISTRATOR

Opinnionaire included the philosophy and goal of the Ashram (Hospice), status of palliative care (for the year 2001, types of cancer patient, age and sex of patients, duration of stay in Ashram), place and pattern of death, how do they meet with stress of patient's death as health professionals.

Based on the Opinnionaire the following information were collected :

Patients are referred by doctors or friends when there is no hope or further treatment. The age range is 0-100 years though the maximum patient died between the age range of 51-60 years. Patients came from all religious groups. All the patients knew that they are suffering from terminal cancer. Out of 182 patients admitted in the year 2001, 132 died and rest left the Ashram. One patient is staying, as she has no one to look after her.

VI RESPONSE OF RELATIVES

The attending doctors who informed the relatives about the terminal stage of cancer referred the patients to the ashram. Relatives were hopeful about recovery. They also expressed their satisfaction in the "peaceful at-

mosphere and caring attitude of everyone". However, each of them expressed that, if death comes, they would like it to happen at home, amongst their other family members and relatives.

VII RESPONSE OF PATIENTS

The patients were referred to the Ashram by doctors treating them for cancer. Most of the patients had hoped to recover in spite of the knowledge that cancer is in terminal stage (as they were relieved of pain, could sleep well and had no constipation). The whole set up was explained as "very peaceful with affectionate, loving and caring sisters". "It is like a place of worship," said one patient. They felt as if they were living in a family at home with specialized and constant care.

VIII RESPONSE OF HEALTH WORKERS

The education level of health workers was between 10 to 12 years of schooling; training was given on the job for non-technical tasks. They empathized with the patients and relatives, Health worker's age varied between 15-22 years. They expressed sadness on death of patients but also expressed that they knew patients have come to die here, so they try to give the best of care. All of them expressed that the moment their family members call they will return home.

IX INSTITUTIONAL EXPERIENCES IN IMPARTING PALLIATIVE CARE BY SR. LIMA, A NURSE ADMINISTRATOR

The concepts of palliative care and the hospice philosophy is not well known or understood by people.

People expect private nursing home facilities with doctors round the clock.

The word 'Ashram' is misinterpreted as a 'place for destitute'. Care of the dying in an Ashram is perceived as family members abandoning patients or not wanting to care for them at home.

Patients are not informed clearly by Oncologists and medical practitioners. They are advised to return to the hospital for further investigations and treatment. Patients are not informed of their terminal conditions so they can discontinue expensive treatment and receive physiological and psychological quality of life care in their last stages.

People come to enquire about services and facilities but very few return with their patients.

As per Sr. Lima, once admitted, patients and their families express deep satisfaction, appreciation and gratitude. There has been no negative feedback.

It was expressed that all patients regardless of type of cancer, move from severe pain, distress and anxiety to a stage of relative normalcy. Their decline and demise is always peaceful.

She further mentioned that patients and families settle down very quickly. Their sense of relief is marked and noticeable from distress to peacefulness.

X. INTEGRATION OF SPIRITUALITY IN HOSPICE CARE

Spirituality has a strong role in the care of the patients and in giving solace to the relatives in the Hospice set up. Reading of Bhagvat Gita for Hindus, Bible for Christians, Gurumukhvani for Sikhs and Quran for Muslims is a part of daily routine. This freedom to worship God according to one's own faith provides a very peaceful environment.

In the words of patient :

"Is it entering in this environment, which is so spiritual that I have started recovering from pain and have good sleep? I have total peace of mind. No emotional and worldly involvement anymore".

In the words of Relative:

"I do feel bad about my patient, but the spiritual atmosphere provides complete peace. The restlessness, the worries have been reduced after entering in the Ashram".

In the words of the Nurses

"We do not know what happens. But it is amazing to see the patient who is bleeding stops bleeding. Pain is reduced. Constipation is relieved and patient gets up fresh in the morning. They say it may be spirituality, which plays a role. All the religious books, are available. The prayer room provides the relatives with sitting place where they can be with their loved ones when they die peacefully. Participation of relatives in the Last Rites gives them satisfaction. It is customary to put Ganges water in the mouth of Hindus and Anointing of the sick for Christians. →

All these facilities are available in the Ashram."

Experience of the Author

"As I visited this Ashram I had a feeling of peaceful, serene and comfortable environment. Patients and relatives were eager to talk. The Physical set up created an atmosphere of care and concern. Outside in the garden of this Ashram, there is a tree in the centre with meditation figures, which motivate tht patients of all religion to meditate for attaining inner peace".

XIII CONCLUSION BY THE AUTHOR

The 36 bedded hospice/ Ashram is under occupied as only 7 to 10 patients are using the facilities.

Patients and relatives need not be informed that no treatment will be effective and the Ashram/ Hospice will provide peaceful and dignified death.

There is a need to create awareness to the public about availability of such kind of care for the life limiting diseases.

Awareness needs to be created amongst the health professionals about the care of patient in the life limiting diseases.

Use of mass media, (Print and Electronic Media) is essential

The name of Ashram is misleading it may be termed as Hospice/Hospital for terminally ill.

The nurses and health workers need to take leave or off in between (after 4 to 8 weeks) to reduce the stress of death and dying

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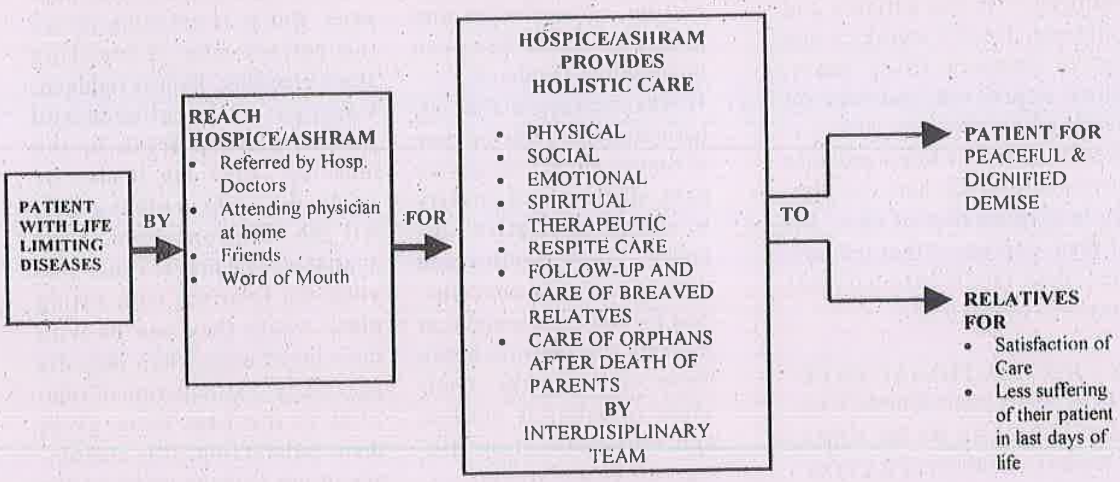

Fig. 1
SCHEMATIC MODEL OF HOLISTIC CARE AT HOSPICE/ASHRAM IN INDIA