

Moments of Life

made possible by Hospice...

|| SAMVEDANA ||

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“Moments Of Life: made possible” by Hospice „SAMVEDANA“

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Abstract

Introduction: Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification, assessment and treatment of pain, and other problems – physical, psychosocial, and spiritual.

Objective: The goal of Moments of Life: Made Possible by Hospice “SAMVEDANA” is to make aware the public about the choices we all have when facing a life-limiting illness and start having benefit of it to reduce their agony.

The Aim is “To put life into their days and not just days into their life” - The idea is to help the person have a meaningful life, not just to live somehow till deaths concerned with quality of life.

Materials and Methods: This was achieved with a study of 21 patients attended day care hospice during three- month study period. McGill quality of life questionnaire, and a new measure of patient satisfaction with hospice care were used.

Result: All patients were getting appropriate psychosocial and spiritual support in addition to the medical / nursing interventions. Palliative care at Hospice Samvedana Affirms:

1. Life and regards dying as a normal process.
2. Neither hastens nor postpones death.
3. Provides relief from pain and other distressing symptoms.
4. Is a team approach.
5. Is individual specific – depends on assessment of patient and family needs.
6. Shifts emphasis from technology to people – “high touch-low tech”.
7. Is a partnership between the patient & the team.

Conclusion: It can be concluded that satisfaction with hospice care was associated with quality of life more than symptoms. Patients can assess their care and can provide valuable information for improving palliative care.

Training of medical officers and health care professionals, and sensitization of the public through awareness campaigns are vital to improve the scope and coverage of palliative care. Process of translating palliative care plan into action requires strong leadership, competent management, political support and integration across all levels of care.

Keywords: Samvedana, palliative care, hospice, Patient satisfaction, Quality of life.

Introduction and Objectives



It is estimated that in India the total number of people who need palliative care is likely to be 5.4 million people a year. However there has been steady progress in the past few years through community-owned palliative care services. One of the key objectives of the National Programme for prevention and control of cancer, diabetes, cardiovascular diseases, and stroke is to establish and develop capacity for palliative and rehabilitative care.

The WHO defined palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual."

The goal of palliative care is, therefore, to improve the quality of life of both patients and families by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psycho-social and spiritual support.

This is why it is best administered by an interdisciplinary, multi-dimensional team, comprising doctors, nurses, counselors, social workers dietician and volunteers Spiritual and Bereavement Coordinator.

Many patients with advanced cancer will develop physical and psychological symptoms related to their disease. These symptoms are infrequently treated by conventional care. Palliative care programs have been developed to fill this gap in care.

The need of palliative care in India is immense

Materials and Methods

Jamnagar Cancer Research Institute is 26 year old NGO serving at Jamnagar district is working for the awareness of cancer in public Our aim is to make society cancer free and early awareness about the symptoms of cancer, inaugurated day care **Hospice || SAMVEDANA ||** on September 2017 at Indumadhu Hospital.

We are offering free pickup and drop from their home. In between 02:00 pm to 07:00 pm. at ||SAMVEDANA|| our schedule is like this.

02:00 to 03:00 pm: Yog Nindra and Meditation

03:00 to 04:00 pm: Laughter Therapy

04:00 to 04:30 pm: Tea and Snacks

04:30 to 05:30 pm: Library and T.V. Show

05:30 to 06:30 pm: Entertainment by Various games

06:30 to 07:00 pm: Prayer and back to home

At the same time doctor look after their physical ailments.

On 14th October we celebrated Hospice Day with them with various rogrammes. Our members celebrate birthday, special days and occasions with them, arranged picnic to various pilgrimage every month.

In modern medicine the traditional way of assessing change in patients has been to focus on laboratory or clinical tests. At its most simple this involves measuring pulse, blood pressure, and temperature, and carrying out physical examinations. At more complex levels it may include haematological analysis, computed tomography, radiography, organ function tests, genetic analysis, and other investigations. While these give important information about the disease, especially about chronic and progressive diseases, it is impossible to separate disease from an individual's personal and social context. No illness exists in a vacuum.

One way of capturing the personal and social context of patients is to use quality of life measures. These are accepted as outcome measures in clinical research but are rarely used in routine clinical practice, despite the fact that Florence Nightingale was one of the first clinicians to insist on measuring the outcome of routine care to evaluate treatment.

1. Using quality of life measures in clinical practice ensures that treatment and evaluations focus on the patient rather than the disease
2. The measures are potentially useful in both the clinical encounter and in quality improvement
3. They are not a substitute for measures of disease outcomes and may not always be the most appropriate patient centred outcome to assess
4. Measures developed for research often cannot easily be used in clinical practice
5. Measures that form an integral part of treatment planning and evaluation are more likely to influence clinical decision making than those that are used only to monitor disease or treatment

Table 1: Age group, cancer part, socio economic status, male/female, their effect

S. No.	Age group	No. of Patients	Sex	
			Male	Female
1	< 50 yrs	4	6	1
2	51 to 60 yrs	9	5	4
3	61 to 70 yrs	6	5	1
4	71 to 80 yrs	2	2	0

Table 2: Types of Cancer

S. No.	Types of Cancer	No. of Patients
1	CA Head and Neck	12
2	CA Breast	5
3	CA Rectum	1
4	CA Lung	2
5	CA Testis	1

Result and Discussion

Most of the patients have pain, sleeplessness, constipations, Tiredness and patients of Tongue and neck cancer have difficulty in swallowing. Pain was of moderate nature of present situation in 70% of patients. In 30% of patients was of wild nature. Social background of 85% of patients are poor to very poor. Patients was only arning member in 60% of cases. Other earning member are also of uneducated type workers.

15% patients were middle class but arranged for their future life. Many patients have Maa – Vatsalya Card, our volunteer managed to get Maa – vatsalya card for other and help in getting Rs. 12000/- per year from Government.

80% paientes were aware about their cancer but 20% are still in ignorance. Reaction of 20% patients on knowing their diagnosis was accepting the deases with courage but remaining are depreassed by various type of difficulties faced by them during treatment scheduled but our Spiritual healers make the comfortable. Pity-based response creates unhelpful reaction to patients' suffering. In contrast, empathy and compassion were welcomed and valued by patients sharing attributes of acknowledging, understanding, and resonating emotionally. Compassionate feelings produced a positive effect, activating regions of the brain associated with reward, love, and affiliation.

Yoga, Laughter Therapy, and Counselling make their life bearable.

Yognindra of 20 minutes is equivalent to 6 hour sleep. Regularize their systems. Patients look future after these session.

After completing chemotherapy and radio therapy many are willing to do suitable job. Our team healed them out to do household work to ladies, job of driver as helper. Such discussions at family meetings lead to lower costs and a lighter family burden (Wright et al.

2008, 2010) and improve family satisfaction and bereavement outcomes (Wright et al. 2008; Zhang et al. 2009)

In saurashtra tobacco addiction is the major culprit for cancer. In some patient radiotherapy was going on, follow up at different interval at Ahmedabad. Cancer patients seek help from alternate pathies like Ayurved, naturopathi, homeopathi it was not healpful in diagnosing or curative face but increase their immunity and cancer free interval.

These objectives are achieved through care provided by interdisciplinary teams of physicians, nurses, social workers, spiritual counselors, pharmacists, aides, and additional personnel as needed (physical therapists, psychologists, and others).

Many don't really understand how hospice works, how it is paid for, the scope of services offered, or the level of expertise the hospice team brings to every patient.

The campaign is also about capturing vivid, emotionally powerful 'moments' on video that will hopefully shatter myths and change minds. One will find stories from the patient, family caregiver, and hospice professional's point of view. And may be surprised to see how much more 'living' is still possible in the last chapter of life.

After all Hospice care helps patient and his family cope with the change from fighting cancer to living life as fully as possible through the very end of life.

Conclusion

The four cardinal principles of palliative care are:

1. Non-maleficence (Do no harm)
2. Beneficence (Do good)
3. Patient autonomy (patient's right to be informed and involved in decision making)
4. Justice (balancing needs of individuals with that of society)

The four cardinal principles need to be applied against a background of:

1. Respect for life
2. Acceptance of the ultimate inevitability of death.
3. The potential benefits of treatment as against the potential risks and burdens
4. Striving to preserve life but, when the burden of life-sustaining treatments outweigh the potential benefits, withdrawing or withholding such treatments and providing comfort in dying
5. Individual needs balanced against those of society.

All four domains of the WHO Public Health Strategy for Palliative Care are best developed simultaneously, and there is clear need for work to define the core competencies and service configurations required for the delivery.

Access to essential medications remains a challenge and must be tackled through national advocacy, education and support.

The palliative care movement is one example of how health services can go well beyond the biomedical model of health and be seen as an affirmative act of living with dignity even whilst accepting that death is an inevitable part of life. Continued efforts are needed to overcome the barriers to successful implementation of palliative care. Ways to integrate current palliative care knowledge into care of patients include multidisciplinary educational initiatives, research endeavors, and clinician resources. Still, a lot needs to be done for creating awareness and training in Palliative Care.

Future Scope

The process of translating palliative care plan into action requires strong leadership, competent management, and political support.

Community models for the provision of home-based palliative care need to be implemented all over the country. Public education and information campaigns are therefore critical to changing public attitudes.

Activities and education campaigns around 'World Hospice and Palliative Care day' (8th October) can increase awareness among the public. Empowerment of family members and volunteers to be effective palliative caregivers might prove to be the most realistic approach for meaningful coverage, especially in rural areas. Healthcare professionals should be trained adequately in palliative care and the foundation of sensitization can be laid by including palliative care in the MBBS curriculum. Incorporating palliative care in existing health systems requires the training of medical officers at the primary health centers and community health centers and the provision of the minimum required facilities for provision of care.

Palliative care standards should be developed with the wide participation of stakeholders, to ensure fulfillment of minimum service requirements. Evidence-based standards of palliative care services and research focusing on improving palliative care services are required in all settings.

Several of these initiatives have been initiated in India; however, concerted effort is required to bring palliative care into the forefront. Future scope for palliative care in the country lies in the provision of facilities and medicines, sustainability of services, support from the community, government, and media and team building for palliative care.

*Let's hope for a pain free India.
"Together everyone achieves more."*

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