

Dying and End of Life Health Care

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Abstract : End of life care is very pivotal for patients on palliative care and their family. Patients have symptoms like pain, nausea & vomiting that needs to be resolved, besides diet, rest and sleep is essential and needs interventions to be managed. Use of life sustaining treatment and supportive measures is part of routine care for patients and family, but social, physical constraints of illness, feeling of emotional isolation, loneliness meeting spiritual needs are imperative for a holistic care for patients in hospital. The concept of EOL care has matured with time, it delivers comfort for dying patient and addresses family to deal with the condition which is difficult. EOLC provide specialized treatment to people whose illness is not curable, terminally ill. It affords quality care as all humans are mortal and in hospital all expect a bonus of days or months to fulfil un-finished dreams and responsibility toward family friends, society and personal aspirations. The primary goal of EOLC is to provide comfort and care to patients as well as family members. EOLC aims at beliefs, customs and values and it vary depending on the cultural and religious background of patient. Care at the end of life should recognize assess and address psychological, social, spiritual/religious issues of patient alone. A study was conducted at Apollo hospital Delhi for newly inducted staff nurses with a structured opinion based questionnaire with convenience sample of 100 nurses to elicit attitude towards end of life care of patients as nurses witnessing birth and end of life is a routine happening in the hospital environment and the aim was to make nurses sensitive to end of life issues. Pre-test followed by training nurses during induction to deal with EOLC followed by post-test. Results demonstrated positive opinions in relation to care at the end of life care from nurse's perspective.

Keywords:- End of life care (EOLC), symptom management, terminally ill. Physical needs.

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I. Introduction

Death is inevitable, we as professionals can help patients and family to accept end of life "In medicine, nursing and the allied health professions, End-of-life care (or EOLC) refers to health care, not only of patients in the final hours or days of their lives, and those with a terminal illness. It's truly a privilege to be there at the bedside of a dying patient and for the family. At Apollo hospital every single situation is a challenge to learn something. Dying is not being in the ICU, multiple tubes coming out, beeping everywhere, family is outside, doctors surrounding with their computers. That's not what dying should be. Dying is a social, family, personal event. And death can take place as part of family occurrence where one belongs.

Objectives Of Research

1. To assess the level of nurse's knowledge regarding end of life care.
2. To assess the attitude of nurses regarding end of life care.
- 3 To associate the knowledge and attitude of nurses regarding end of life care with their demographic data.

II. Material & methods

Methods of Study & Research Design

One-group pre-test-post-test research design was chosen with 100(N100) newly joined staff nurses to determine the effect of induction training on newly joined staff nurses to address behavioural changes and attitude towards EOLC. A linear pattern was adopted to assess the dependent variable (newly joined staff nurses) before and after implementing induction training the pre-test-post-test research design determined the difference between the first assessments of the dependent variable. A structured opinion based questionnaire was used. A convenient sample of 100 newly inducted staff nurses were taken during their induction training period of one month to elicit attitude towards end of life care of patients.

Study location: -conducted at Apollo Hospital at Delhi.

Study duration: - One day

Sample size: - 100

Subjects and selection method:-

Inclusive criteria:-

All newly joined nurses present on the day of study

All newly joined nurses irrespective of their educational qualification (ANM, GNM BSc Nursing)

All newly joined nurses irrespective of their age

All newly joined nurses irrespective of their area of work/work experience.

Exclusive criteria

Nurses who have completed induction training

Nurses who are absent on the day of study

Procedure Methodology

Development of questionnaire:

The questionnaire was developed based on knowledge in order to assess attitude of nurses towards end of life care of patients .The questionnaire was designed to collect participant's demographic details and 23 items on five category questionnaire.We developed an opinion based questionnaire in order to assess attitude of nurses towards end of life care of patient

Basic needs that were apparent are

• **Physical** – managing symptoms such as pain, sickness, tiredness or loss of appetite; as preventing pressure sores

• **Psychological** – giving emotional support to the attendant and those who care about them, giving time to listen to them and understand their concerns.

• **Social** – giving support and advice on practical matters such as getting their legal affairs in order

• **Spiritual** – a need to explore thoughts about the meaning of life, or concerns about what happens after death. All people are likely to have spiritual needs and some may also have practical things they need to do because of their religious beliefs

All staffs assigned for the patient should be ready to listen to patients nearing the end of life, to address their needs if possible and to seek expert help where extra skill or knowledge is needed.

Supportive care

Supportive care is very important part in treatment, diagnosis and to cope with the disease condition or peaceful death into bereavement. (Focus on Care Homes, National Council for Palliative Care)Providing good End of life medical care is not enough, providers must become more skilled at having effective end of life conversations.

Major barriers and challenges faced to manage end of life care include:

• Language and medical interpretations.

• Religious or spiritual belief of the patient and family.

• Provider ignorance of patient's cultural beliefs values and practices.

• Cultural differences among patients and family in accepting the truth about prognosis and in decision making.

• The Patient's level of health literacy.

•The level of patients mistrust of doctors and the health care systems in general.

Treatment may always be the best option. Dying in India has become extremely expensive, with a huge proportion of Medicare's budget spent on treatment during the last years of life where there is little hope for recovery.

Hospice

The approach to help someone to die with dignity or good death needs hospice frame work Hospice aims at providing symptom control and attention psychological / spiritual concerns . Thus this framework analyses a person's medical care into four major topics, and this can be used to outline day to day care plans for patient.

Symptom control including dyspnoea, nausea, confusion, delirium, skin problems and oral care.

Psychological problems like depression, sadness, anxiety, fear and loneliness.

Spiritual issues – which includes religious and non-religious beliefs about the nature of illness and diagnosis.

It is estimated that in India , at any point of time there are 3 million patients living with advance stage of chronic illness like Cancer and other incurable illness .There is sizable populations of patients with HIV/AIDS and the

geriatric population is increasing every year and all of them are in dire need of hospice care service. India does not cater for this need.

Addressing the non-physical needs.

Palliative care provides pain relief as well meets spiritual and emotional support. In fact, some participants claimed that addressing the patient's psychosocial issues can help moderate their physical symptoms, thereby ensuring they are mentally and physically free.

Patient wishes are honoured.

Incorporated in the concept of honouring wishes was an emphasis on 'place of death'. It was observed that, patients have an opinion on where they want to die and need to be informed of the available options. In some instances, attendants speak of experiences where they did not agree with the wishes of the patient, and yet recognised that these differences in opinion have to be respected.

Addressing the physical needs

Addressing the patient's physical needs, which encompass pain and symptom management, and ensuring the patient is comfortable at all times, is important to many of the attendants. Also derived from the responses was the prevailing fear of pain itself. Many providers spoke of the fear that both patients and caregivers felt due to the uncertainty of how intense the pain would become in the days ahead.

Breaking Bad News

Informing the family members about the sudden death of their loved one is a highly stressful experience for the medical team in hospital settings and has serious affects but it is essential skill for all health care professionals

Facilitating the grief reaction

Having announced the bad news, the counsellor's next duty is to help the relatives to go through the process of grief. Encourage the relatives to express their feelings like crying loudly or sobbing etc. Encourage them to talk about the patient's illness, and if they open up, try to explain the efforts taken to save him and the inevitable outcome. Remaining silent with physical touch like placing hand on the sobbing person's hand or head may be tried depending upon the situation and ethnic background. Appreciating the efforts taken by the relatives to get the patient treated may help them to come out of a sense of guilt or self-blame. Convince them again that there has been no shortage of efforts either from the health care team or from the relative's. In certain cases, especially when the diseased has been in deep coma, explain them how peaceful the death was. This would help to convince them that their beloved one did not suffer much. Such reassurances also reduce guilt feelings

Some amounts of religious philosophy like "ultimately everything depends on God's wish" or "Life-span being over as per God calculation" etc., may help to console the bereaved relatives, and again, this depends on ethnicity and religious background. Do not respond or argue with the relatives if they blame or comment on the healthcare team or the hospital. They will realize their mistake and surely apologize when the emotions settles down and the crisis situation is over.

III. Result and discussion

Project proved that majority of sample subjects were in age group . 85 % were 19– 25 years and 13 % were 25- 30 years and 2 (2%) were 30 – 35 years. Work experience of majority subjects 90 (90 %) was 0 – 2 years . and 9 (9 %) of them had 2 – 10 years of experience , 1 (1 %) had 10 - 15 years as a staff nurse .

It indicates that majority of sample subjects 80 out of 100 had high attitude score indicating positive attitude on end of life care post induction class. Communication skills among nurses improved, majority of the staff nurses feel confident to listen to and talk with dying patient about issues surrounding their death. In addition, they feel confident to communicate with a patient with advancing illness who says statement like "I have no meaning in life". Also results proved highest positive score was found in Assessment and Care Planning for end of life care patients, where the community felt more aware about holistic assessment with patients

Frequency And Percentage Distribution Of Background Information Of Staff Nurses

N = 100

s. no .	Background information	Frequency	Percentage %
1.	AGE IN YEAR		
	19 -25 years	85	85
	25 -30 years	13	13
	30 -35 years	2	2
2.	Work experience		

	0-2 years	90	90
	2-10 years	9	9
	10 -15 years	1	1
3.	UNIT		
	ICU/HDU	57	57
	GEN. WARD / BLOOD BANK	24	24
	Emergency	10	10
	Others	9	9

Annexure 4 Attitude Score of Registered Nurses

Category	Mean Score	Percentage
1 Communication skills	18	90
2. Assessment and care planning	23	92
3.Symptom management maintaining comfort and well being	18	72
4. Advance care planning	13	86
5.Overarching values and knowledge	20	80

IV. Conclusion

Life for human being is just once we must make the best of it. Compassion is key, responsiveness. Self-respect and dignity for the patient, family, their wishes, their needs, excellence in pain and symptom management, attentiveness to the spiritual needs, and support of the care giving system and family is vital in end of life care. Attendant's satisfaction had increased. The quality of counselling provided to patients and their family members has improved as nurses were educated on end of life issues. This gave positive feedback to our hospital about end of life care. The main focus was to develop family and community oriented approach, which was achieved. Listening is a skill that health care professionals should develop as patients and family are able to ventilate their feeling and they feel loved and cared. It is not length of life that matters but the quality of life that can be rendered to end of life patient. We all will die one day but how we will die is important for all of us. The goal isn't to make patients live forever, but to create a feeling that shows that they are loved & cared. Compassion is expected by everyone irrespective what role they have in the health care system. Dying and death is a very sensitive situation were all with experience and without experience need to handle the situation. Nurses working 24x7 tend to be stressed and sometime may be rude in their dealing ongoing training has facilitated our hospital in dealing compassionately with end of life issues. As a well spent day brings good sleep, so life well ended brings peaceful death and satisfaction to the family and community as a whole.

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