

End of Life Care: Healthcare Provider's Mindset, Needs and Barriers

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ABSTRACT

Introduction: In India, End of Life (EOL) care practice has gained momentum. EOL can have significant impact on physical, emotional and financial aspect. Care planning, coordination and good communication are important if the needs and preferences of people are to be met for their EOL care. There is very minimal information available on awareness, attitude, planning and provision of EOL care.

Aim: To assess the Knowledge, Attitude and Practice (KAP) among hospital administrators, doctors and nurses on EOL care and to the decision-making aspects and possible barriers in the provision of EOL care.

Materials and Methods: A descriptive survey-based study was conducted at the Department of Hospital Administration, Vydehi Institute of Medical Science and Research Centre Bengaluru, Karnataka. The questionnaire was distributed among 100 healthcare providers including hospital administrators, doctors and nurses involved in EOL care. A structured questionnaire containing 15 questions were used to gather data from the respondents wherein question no. 1 to 5 were based on the knowledge and question no. 6 to 13 were based on practice and question no. 14 and 15 were based on the attitude. All data were

entered in MS Excel and statistical analysis was done using the Statistical Package for the Social Sciences (SPSS) Version 20.0.

Results: Majority of respondents belonged to the group ranging from 25-35 years of age, wherein 58 were males and 42 were females. Ninety participants out of 100 were aware of the concept of "EOL care", 59 were aware about the current laws concerning EOL care and 17 participants had their medical staff in the hospital being educated and trained on EOL care ($p>0.05$). Around 29 participants have experienced lack of communication while giving EOL care to patients; 54 out of 100 participants have experienced fury from patient/attender during their practice and 66 participants felt that the hospital should take into consideration of spiritual, religious and cultural beliefs in dealing with EOL care patient. Furthermore, Chi-square test revealed significant ($p<0.001$) relation between the factors such as age of the patient, duration of disease, economic factors, health insurance, patient suffering, emotional distress among patient/attender and no hope of good quality of life in making decision during EOL.

Conclusion: Along with improvements in rules and regulations, there is an urgent need for increasing in awareness among stakeholders who are involved in EOL care practice.

Keywords: Disease, Quality of life, Terminally ill care

INTRODUCTION

The End of Life (EOL) care relates to think about patients with terminal sickness after they have arrived at a phase of significant deterioration, as a rule during the most recent couple of weeks or months before death [1]. EOL care primarily centres around patient's solace, keeping up personal satisfaction and their families through the administration of agony and other psychosocial, physical and profound morbidities, yet centres generally around explicit time period before death [2-4]. Patients at EOL may have exceptionally complex genuine ailments and seem to contribute a high extent of their medical services costs; likewise, strengthening of therapy is as often as possible related with more unfortunate clinical results [1,5-7].

EOL care is often associated with many tough challenges for healthcare providers as well as for patients and their beloved family members as it involves management of pain and suffering along with psychological and emotional distress. Staffs for the EOL consist of specialised doctors, allied health professionals, nurses, and spiritual care workers and they have specialist expertise in symptom management, spiritual, emotional, cultural and practical care [8]. Sadly, those staffs who are answerable for the treatment of patients toward the end of life generally need sufficient preparing to help manage EOL choices and to convey awful news to patient's and families [9,10].

A majority of studies didn't perceive culture and religion as barriers. Religion was ranked the least significant of the reasons given as a

barrier. Indian studies on EOL beliefs propose religion as a major concern for the patients and families [11,12]. Available information about life support withdrawal rates at ICUs is limited in India and available only from two sources [13,14]. A practice review at Intensive Care Units in four Mumbai hospitals revealed inadequacy of care in just 34% of deaths and an extremely low i.e., 8% life support withdrawal incidence [13].

The EOL care movement is one example, of how services of healthcare can go far beyond the biomedical health paradigm and be a positive act of living with respect while acknowledging that death is part of life and is unavoidable. There is a necessity of continuous attempts to overcome obstacles in implementing palliative care effectively. Methods to incorporate current awareness regarding palliative care into patient's care consist of clinician resources, research endeavours and multidisciplinary educational initiatives. With this scenario, the present study was carried out to assess the attitude, prerequisites and hindrances in providing EOL care among hospital administrators, doctors and nurses.

MATERIALS AND METHODS

A descriptive survey-based study was conducted to assess the KAP among hospital administrators, doctors and nurses on EOL care and also to understand decision-making process and possible barriers in the provision of EOL care using a structured questionnaire. Hospital administrators, doctors, and nurses involved in providing EOL care and caregiver available at the time

of the study were included for the study. Care givers not willing to participate in the study were excluded. The study was approved by the Institutional Ethical Committee (IEC) approval committee with IEC approval number VIEC/2019/APP/061. Questionnaire was prepared by the authors with reference to EOL care guidelines given the Indian Association of Palliative Care (IAPC) [15]. Validity and reliability (0.642) of the framed questionnaire was performed by the subject experts from the institute. This questionnaire was given through google forms to 100 healthcare providers (doctors and nurses providing EOL) for a period of 3 months from November 2019 to January 2020 in Bengaluru. The sample size for the study was estimated using below using the given formula. Substituting the values- the Sample Size was calculated to be 100.

$$\text{Sample size} = \{Z^2 \cdot (p) \cdot (q)\} / \Delta^2$$

| | | |
|-------------|---|-------|
| P | Your guess of population P (any value <1) | 0.705 |
| 1- α | Confidence level set by you | 0.9 |
| Z | Z value associated with confidence | 1.64 |
| d | Absolute precision (Value less than P) | 0.075 |
| n | Minimum sample size | 100 |

where

p Your guess of population P (any value <1) 0.705

1- α Confidence level set by you 0.9

Z Z value associated with confidence 1.64

d Absolute precision (Value less than P) 0.075

n Minimum sample size 100

All the participants were asked to fill a structured questionnaire after obtaining informed consent. There was no specific time limit allotted to fill the questionnaire. Responses were tabulated in MS Excel. This questionnaire contained 15 questions related to EOL care. Question no. 1 to 5 were based on the knowledge and question no. 6 to 13 were based on practice and question no. 14 and 15 were based on the attitude. From question no. 1 to 13 responses were collected in the form of yes or no and for question no. 14 and 15 in the form of Likert scale where 5 represented very important and 1 least important (Annexure 1).

STATISTICAL ANALYSIS

All data were entered in MS Excel and statistical analysis was done using the SPSS Version 20.0. For quantitative variables, frequency and proportions for qualitative variables, descriptive statistics of the explanatory and outcome variables was evaluated by mean, SD (standard deviation), median, interquartile range. Inferential statistics like Chi-square test was applied for categorical variables. The significance level of was set at 95% and $p < 0.05$ was considered statistically significant.

RESULTS

In this study, majority of participants i.e., 53/100 (53%) belonged to the age group of 25-35 years followed by 31/100 (31%) in 36-45 years [Table/Fig-1]. There was a male preponderance (58%) as compared to females (42%) [Table/Fig-2]. A total of 56 participants had hands-on EOL care experience of 1 to 5 years; out of 53 participants aged 25 to 35 years, 45 had experience of 1 to 5 years [Table/Fig-3]. More than half i.e., 58 were specialised in critical

| Age (years) | Frequency | Percentage (%) |
|-------------|-----------|----------------|
| 25-35 | 53 | 53 |
| 36-45 | 31 | 31 |
| 46-55 | 9 | 9 |
| Above 55 | 7 | 7 |
| Total | 100 | 100 |

[Table/Fig-1]: Age-wise distribution of the participants.

care out of which 29 aged 25 to 35 years; 19 participants were administrators and 23 were specialised in oncology [Table/Fig-4].

| Gender | | Age (years) | | | | Total |
|---------|---------|-------------|-------|-------|----------|-------|
| | | 25-35 | 36-45 | 46-55 | Above 55 | |
| Females | Count | 17 | 17 | 8 | 0 | 42 |
| | Percent | 32.1% | 54.8% | 88.9% | 0 | 42% |
| Males | Count | 36 | 14 | 1 | 7 | 58 |
| | Percent | 67.9% | 45.2% | 11.1% | 100% | 58% |
| Total | Count | 53 | 31 | 9 | 7 | 100 |
| | Percent | 100% | 100% | 100% | 100% | 100% |

[Table/Fig-2]: Cross-tabulation of age and gender.

*significant

| EOL care experience | | Age (years) | | | | Total |
|---------------------|---------|-------------|-------|-------|----------|-------|
| | | 25-35 | 36-45 | 46-55 | Above 55 | |
| 1 to 5 years | Count | 45 | 11 | 0 | 0 | 56 |
| | Percent | 84.9% | 35.5% | 0 | 0 | 56% |
| 6 to 10 years | Count | 7 | 14 | 0 | 0 | 21 |
| | Percent | 13.2% | 45.2% | 0 | 0 | 21% |
| 11 to 15 years | Count | 0 | 4 | 9 | 0 | 13 |
| | Percent | 0 | 12.9% | 100% | 0 | 13% |
| Above 16 years | Count | 1 | 2 | 1 | 7 | 11 |
| | Percent | 1.9% | 6.5% | 11.1% | 100% | 11% |
| Total | Count | 53 | 31 | 9 | 7 | 100 |
| | Percent | 100% | 100% | 100% | 100% | 100% |

[Table/Fig-3]: Cross-tabulation of age and EOL care experience.

| Speciality | | Age (years) | | | | Total |
|---------------|---------|-------------|-------|-------|----------|-------|
| | | 25-35 | 36-45 | 46-55 | Above 55 | |
| Administrator | Count | 11 | 4 | 0 | 4 | 19 |
| | Percent | 20.8% | 12.9% | 0% | 57.1% | 19% |
| Critical care | Count | 29 | 20 | 8 | 1 | 58 |
| | Percent | 54.7% | 64.5% | 88.9% | 14.3% | 58% |
| Oncology | Count | 13 | 7 | 1 | 2 | 23 |
| | Percent | 24.5% | 22.6% | 11.1% | 28.6% | 23% |
| Total | Count | 53 | 31 | 9 | 7 | 100 |
| | Percent | 100% | 100% | 100% | 100% | 100% |

[Table/Fig-4]: Cross-tabulation of age and speciality.

The results of questionnaire survey on knowledge and practice revealed that 99 out of 100 participants were aware of the concept of EOL. About 28/100 has policy on EOL care in their hospital. Out of 100 participants, 17 told that their staff in the hospital is being educated and trained on EOL care. About 54 out of 100 participants have experienced fury from patient/attender during their practice. Furthermore, 41/100 participants, felt that their hospital provided special support for patient/attender during EOL care [Table/Fig-5]. Chi-square test revealed significant ($p < 0.001$) relation between all the factors such as the patient age, duration of disease, economic factor, health insurance, patient suffering, emotional distress among patient/attender and no hope of good quality of life in future with age [Table/Fig-6]. Furthermore, Chi-square test revealed significant ($p < 0.001$) relation between all the factors; laws, fear of litigation, hospital policies and ethical concerns, cultural and religious factors, external factors (influence of others) with age [Table/Fig-7].

DISCUSSION

The present study was conducted to assess the KAP among hospital administrators, doctors and nurses on EOL care and to understand decision-making aspects and possible barriers in the provision of EOL care. A total of 100 doctors and nurses working

| Survey questionnaire | | | Age (years) | | | | Total | p-value | Chi-square value |
|----------------------|--|---|-------------|-------|-------|----------|-------|---------|------------------|
| | | | 25-35 | 36-45 | 46-55 | Above 55 | | | |
| | | | | | | | | | |
| Q1 | No | N | 0 | 1 | 0 | 0 | 1 | 0.52 | 2.24 |
| | | % | 0 | 3.2 | 0 | 0 | 1 | | |
| | Yes | N | 53 | 30 | 9 | 7 | 99 | | |
| | | % | 100 | 96.8 | 100 | 100 | 99 | | |
| Q2 | No | N | 21 | 19 | 0 | 1 | 41 | 0.003* | 13.63 |
| | | % | 39.6 | 61.3 | 0 | 14.3 | 41 | | |
| | Yes | N | 32 | 12 | 9 | 6 | 59 | | |
| | | % | 60.4 | 38.7 | 100 | 85.7 | 59 | | |
| Q3 | No | N | 10 | 7 | 8 | 6 | 31 | <0.001* | 28.57 |
| | | % | 18.9 | 22.6 | 88.9 | 85.7 | 31 | | |
| | Yes | N | 43 | 24 | 1 | 1 | 69 | | |
| | | % | 81.1 | 77.4 | 11.1 | 14.3 | 69 | | |
| Q4 | No | N | 31 | 28 | 7 | 6 | 72 | 0.013* | 10.76 |
| | | % | 58.5 | 90.3 | 77.8 | 85.7 | 72 | | |
| | Yes | N | 22 | 3 | 2 | 1 | 28 | | |
| | | % | 41.5 | 9.7 | 22.2 | 14.3 | 28 | | |
| Q5 | No | N | 31 | 31 | 7 | 7 | 76 | <0.001* | 20.92 |
| | | % | 58.5 | 100 | 77.8 | 100 | 76 | | |
| | Yes | N | 22 | 0 | 2 | 0 | 24 | | |
| | | % | 41.5 | 0 | 22.2 | 0 | 24 | | |
| Q6 | No | N | 40 | 29 | 8 | 6 | 83 | 0.18 | 4.83 |
| | | % | 75.5 | 93.5 | 88.9 | 85.7 | 83 | | |
| | Yes | N | 13 | 2 | 1 | 1 | 17 | | |
| | | % | 24.5 | 6.5 | 11.1 | 14.3 | 17 | | |
| Q7 | No | N | 44 | 29 | 9 | 4 | 86 | 0.043* | 8.16 |
| | | % | 83 | 93.5 | 100 | 57.1 | 86 | | |
| | Yes | N | 9 | 2 | 0 | 3 | 14 | | |
| | | % | 17.0 | 6.5 | 0 | 42.9 | 14 | | |
| Q8 | No | N | 37 | 21 | 9 | 4 | 71 | 0.21 | 4.52 |
| | | % | 69.8 | 67.7 | 100 | 57.1 | 71 | | |
| | Yes | N | 16 | 10 | 0 | 3 | 29 | | |
| | | % | 30.2 | 32.3 | 0 | 42.9 | 29 | | |
| Q9 | Unanswered | N | 52 | 28 | 9 | 7 | 96 | 0.80 | 7.72 |
| | | % | 98.1 | 90.3 | 100 | 100 | 96 | | |
| | Talk to the nearest blood relative | N | 0 | 1 | 0 | 0 | 1 | | |
| | | % | 0 | 3.2 | 0 | 0 | 1 | | |
| | Frequent counselling | N | 0 | 1 | 0 | 0 | 1 | | |
| | | % | 0 | 3.2 | 0 | 0 | 1 | | |
| | Training the healthcare professionals | N | 1 | 0 | 0 | 0 | 1 | | |
| | | % | 1.9 | 0 | 0 | 0 | 1 | | |
| Q10 | No | N | 37 | 9 | 0 | 0 | 46 | <0.001* | 29.32 |
| | | % | 69.8 | 29 | 0 | 0 | 46 | | |
| | Yes | N | 16 | 22 | 9 | 7 | 54 | | |
| | | % | 30.2 | 71 | 100 | 100 | 54 | | |
| Q11 | No response | N | 49 | 29 | 9 | 7 | 94 | 0.92 | 8.07 |
| | | % | 92.5 | 93.5 | 100 | 100 | 94 | | |
| | Anxiety | N | 0 | 1 | 0 | 0 | 1 | | |
| | | % | 0 | 3.2 | 0 | 0 | 1.0 | | |
| | Denial of end of life | N | 1 | 0 | 0 | 0 | 1 | | |
| | | % | 1.9 | 0 | 0 | 0 | 1.0 | | |
| | Denial, frustration | N | 0 | 1 | 0 | 0 | 1 | | |
| | | % | 0 | 3.2 | 0 | 0 | 1 | | |
| | Emotions and unwillingness to accept an adverse outcome. | N | 2 | 0 | 0 | 0 | 2 | | |
| | | % | 3.8 | 0 | 0 | 0 | 2 | | |
| | Grief of patient attenders | N | 1 | 0 | 0 | 0 | 1 | | |
| | | % | 1.9 | 0 | 0 | 0 | 1.0 | | |

| | | | | | | | | | |
|-----|-----|---|------|------|------|------|----|-------|------|
| Q12 | No | N | 21 | 13 | 0 | 0 | 34 | 0.02* | 9.85 |
| | | % | 39.6 | 41.9 | 0 | 0 | 34 | | |
| | Yes | N | 32 | 18 | 9 | 7 | 66 | | |
| | | % | 60.4 | 58.1 | 100 | 100 | 66 | | |
| Q13 | No | N | 32 | 17 | 8 | 2 | 59 | 0.09 | 6.26 |
| | | % | 60.4 | 54.8 | 88.9 | 28.6 | 59 | | |
| | Yes | N | 21 | 14 | 1 | 5 | 41 | | |
| | | % | 39.6 | 45.2 | 11.1 | 71.4 | 41 | | |

[Table/Fig-5]: Cross-tabulation of survey questionnaire and age.

*p-value <0.001 was considered significant

for EOL from Bengaluru participated in the survey. In our study, according to the demographic characteristics data, majority of participants belonged to age group of 25-35 years i.e., 53/100 (53%). Out of 100 participants, 58 were males and 42 were females, out of 53 participants aged 25 to 35 years, 36 were males and 17 were females. This is in contrast to study of Nadin S et al., majority of participants (42.5%) were in 55-64 years age group and most of them were females (70.1%) than males (26.9%) [16].

| Factors | | | Age (years) | | | | Total | p-value | Chi-square value |
|--------------------|---------------------|---|-------------|-------|-------|----------|-------|---------|------------------|
| | | | 25-35 | 36-45 | 46-55 | Above 55 | | | |
| | | | | | | | | | |
| Laws | Extremely important | N | 23 | 18 | 2 | 3 | 46 | 0.001* | 60.45 |
| | | % | 43.4 | 58.1 | 22.2 | 42.9 | 46 | | |
| | Very important | N | 17 | 6 | 0 | 4 | 27 | | |
| | | % | 32.1 | 19.4 | 0 | 57.1 | 27 | | |
| | Quite important | N | 2 | 6 | 0 | 0 | 8 | | |
| | | % | 3.8 | 19.4 | 0 | 0 | 8 | | |
| | Somewhat important | N | 5 | 0 | 7 | 0 | 12 | | |
| | | % | 9.4 | 0 | 77.8 | 0 | 12 | | |
| | Unimportant | N | 0 | 1 | 0 | 0 | 1 | | |
| | | % | 0 | 3.2 | 0 | 0 | 1 | | |
| Fear of litigation | Extremely important | N | 19 | 11 | 1 | 3 | 34 | 0.001* | 36.80 |
| | | % | 35.8 | 35.5 | 11.1 | 42.9 | 34 | | |
| | Very important | N | 27 | 16 | 0 | 4 | 47 | | |
| | | % | 50.9 | 51.6 | 0 | 57.1 | 47 | | |
| | Quite important | N | 7 | 3 | 8 | 0 | 18 | | |
| | | % | 13.2 | 9.7 | 88.9 | 0 | 18 | | |
| | Somewhat important | N | 0 | 1 | 0 | 0 | 1 | | |
| | | % | 0 | 3.2 | 0 | 0 | 1 | | |
| | Unimportant | N | 0 | 0 | 0 | 0 | 0 | | |
| | | % | 0 | 0 | 0 | 0 | 0 | | |
| Hospital policies | Extremely important | N | 15 | 14 | 0 | 0 | 29 | 0.001* | 69.69 |
| | | % | 28.3 | 45.2 | 0 | 0 | 29 | | |
| | Very important | N | 32 | 9 | 1 | 5 | 47 | | |
| | | % | 60.4 | 29 | 11.1 | 71.4 | 47 | | |
| | Quite important | N | 6 | 6 | 1 | 2 | 15 | | |
| | | % | 11.3 | 19.4 | 11.1 | 28.6 | 15 | | |
| | Somewhat important | N | 0 | 2 | 7 | 0 | 9 | | |
| | | % | 0 | 6.5 | 77.8 | 0 | 9 | | |
| | Unimportant | N | 0 | 0 | 0 | 0 | 0 | | |
| | | % | 0 | 0 | 0 | 0 | 0 | | |
| Ethical concerns | Extremely important | N | 23 | 13 | 0 | 2 | 38 | 0.001* | 32.87 |
| | | % | 43.4 | 41.9 | 0 | 28.6 | 38 | | |
| | Very important | N | 24 | 17 | 2 | 4 | 47 | | |
| | | % | 45.3 | 54.8 | 22.2 | 57.1 | 47 | | |
| | Quite important | N | 6 | 1 | 7 | 1 | 15 | | |
| | | % | 11.3 | 3.2 | 77.8 | 14.3 | 15 | | |
| | Somewhat important | N | 0 | 0 | 0 | 0 | 0 | | |
| | | % | 0 | 0 | 0 | 0 | 0 | | |
| | Unimportant | N | 0 | 0 | 0 | 0 | 0 | | |
| | | % | 0 | 0 | 0 | 0 | 0 | | |

| | | | | | | | | | |
|--------------------------------|---------------------|---|------|------|------|------|----|--------|-------|
| Cultural and religious factors | Extremely important | N | 7 | 3 | 2 | 5 | 17 | 0.001* | 29.38 |
| | | % | 13.2 | 9.7 | 22.2 | 71.4 | 17 | | |
| | Very important | N | 11 | 11 | 0 | 1 | 23 | | |
| | | % | 20.8 | 35.5 | 0 | 14.3 | 23 | | |
| | Quite important | N | 19 | 8 | 7 | 1 | 35 | | |
| | | % | 35.8 | 25.8 | 77.8 | 14.3 | 35 | | |
| Somewhat important | | N | 16 | 9 | 0 | 0 | 25 | 0.001* | 29.38 |
| | | % | 30.2 | 29 | 0 | 0 | 25 | | |
| | Unimportant | N | 0 | 0 | 0 | 0 | 0 | | |
| | | % | 0 | 0 | 0 | 0 | 0 | | |
| | Extremely important | N | 20 | 1 | 2 | 3 | 26 | | |
| | | % | 37.7 | 3.2 | 22.2 | 42.9 | 26 | | |
| Very important | | N | 5 | 5 | 0 | 1 | 11 | 0.001* | 62.38 |
| | | % | 9.4 | 16.1 | 0 | 14.3 | 11 | | |
| | Quite important | N | 6 | 13 | 0 | 1 | 20 | | |
| | | % | 11.3 | 41.9 | 0 | 14.3 | 20 | | |
| | Somewhat important | N | 21 | 0 | 7 | 1 | 29 | | |
| | | % | 39.6 | 0 | 77.8 | 14.3 | 29 | | |
| Unimportant | | N | 1 | 12 | 0 | 1 | 14 | 0.001* | 62.38 |
| | | % | 1.9 | 38.7 | 0 | 14.3 | 14 | | |

[Table/Fig-6]: Cross-tabulation of age and factors.

*p-value <0.001 was considered significant

| Factors | | | Age (years) | | | | Total | p-value | Chi-square value |
|---------------------|---------------------|---|-------------|-------|-------|----------|-------|---------|------------------|
| | | | 25-35 | 36-45 | 46-55 | Above 55 | | | |
| Age of the patient | Extremely important | N | 34 | 21 | 2 | 7 | 64 | 0.001* | 53.24 |
| | | % | 64.2 | 67.7 | 22.2 | 100 | 64 | | |
| | Very important | N | 9 | 7 | 0 | 0 | 16 | | |
| | | % | 17 | 22.6 | 0 | 0 | 16 | | |
| | Quite important | N | 3 | 1 | 7 | 0 | 11 | | |
| | | % | 5.7 | 3.2 | 77.8 | 0 | 11 | | |
| Somewhat important | | N | 2 | 2 | 0 | 0 | 4 | 0.001* | 53.24 |
| | | % | 3.8 | 6.5 | 0 | 0 | 4 | | |
| | Unimportant | N | 5 | 0 | 0 | 0 | 5 | | |
| | | % | 9.4 | 0 | 0 | 0 | 5 | | |
| | Extremely important | N | 28 | 13 | 2 | 6 | 49 | | |
| | | % | 52.8 | 41.9 | 22.2 | 85.7 | 49 | | |
| Duration of disease | Very important | N | 10 | 14 | 0 | 1 | 25 | 0.001* | 38.10 |
| | | % | 18.9 | 45.2 | 0 | 14.3 | 25 | | |
| | Quite important | N | 6 | 3 | 0 | 0 | 9 | | |
| | | % | 11.3 | 9.7 | 0 | 0 | 9 | | |
| | Somewhat important | N | 9 | 1 | 7 | 0 | 17 | | |
| | | % | 17 | 3.2 | 77.8 | 0 | 17 | | |
| Unimportant | | N | 0 | 0 | 0 | 0 | 0 | 0.013* | 29.59 |
| | | % | 0 | 0 | 0 | 0 | 0 | | |
| | Extremely important | N | 14 | 5 | 0 | 4 | 23 | | |
| | | % | 26.4 | 16.1 | 0 | 57.1 | 23 | | |
| | Very important | N | 14 | 6 | 2 | 2 | 24 | | |
| | | % | 26.4 | 19.4 | 22.2 | 28.6 | 24 | | |
| Quite important | | N | 15 | 12 | 0 | 1 | 28 | 0.013* | 29.59 |
| | | % | 28.3 | 38.7 | 0 | 14.3 | 28 | | |
| | Somewhat important | N | 7 | 7 | 7 | 0 | 21 | | |
| | | % | 13.2 | 22.6 | 77.8 | 0 | 21 | | |
| | Unimportant | N | 2 | 1 | 0 | 0 | 3 | | |
| | | % | 3.8 | 3.2 | 0 | 0 | 3 | | |
| No response | | N | 1 | 0 | 0 | 0 | 1 | 0.013* | 29.59 |
| | | % | 1.9 | 0 | 0 | 0 | 1 | | |

| | | | | | | | | | |
|---|---------------------|---|------|------|------|------|------|--------|-------|
| Health insurance | Extremely important | N | 5 | 1 | 0 | 0 | 6 | 0.008* | 31.36 |
| | | % | 9.4 | 3.2 | 0 | 0 | 6 | | |
| | Very important | N | 12 | 11 | 1 | 5 | 29 | | |
| | | % | 22.6 | 35.5 | 11.1 | 71.4 | 29 | | |
| | Quite important | N | 15 | 6 | 1 | 2 | 24 | | |
| | | % | 28.3 | 19.4 | 11.1 | 28.6 | 24 | | |
| Somewhat important | | N | 9 | 3 | 0 | 0 | 12 | 0.008* | 31.36 |
| | | % | 17.0 | 9.7 | 0 | 0 | 12 | | |
| | Unimportant | N | 7 | 8 | 7 | 0 | 22 | | |
| | | % | 13.2 | 25.8 | 77.8 | 0 | 22 | | |
| | No response | N | 5 | 2 | 0 | 0 | 7 | | |
| | | % | 9.4 | 6.5 | 0 | 0 | 7 | | |
| Patient suffering | Extremely important | N | 38 | 15 | 1 | 6 | 60 | 0.01* | 38.91 |
| | | % | 71.7 | 48.4 | 11.1 | 85.7 | 60 | | |
| | Very important | N | 10 | 8 | 8 | 1 | 27 | | |
| | | % | 18.9 | 25.8 | 88.9 | 14.3 | 27.0 | | |
| | Quite important | N | 4 | 1 | 0 | 0 | 5 | | |
| | | % | 7.5 | 3.2 | 0 | 0 | 5 | | |
| Somewhat important | | N | 0 | 7 | 0 | 0 | 7 | 0.01* | 38.91 |
| | | % | 0 | 22.6 | 0 | 0 | 7 | | |
| | Unimportant | N | 0 | 0 | 0 | 0 | 0 | | |
| | | % | 0 | 0 | 0 | 0 | 0 | | |
| | No response | N | 1 | 0 | 0 | 0 | 1 | | |
| | | % | 1.9 | 0 | 0 | 0 | 1 | | |
| Emotional distress among patient/attender | Extremely important | N | 17 | 6 | 9 | 7 | 39 | 0.01* | 45.72 |
| | | % | 32.1 | 19.4 | 100 | 100 | 39 | | |
| | Very important | N | 17 | 22 | 0 | 0 | 39 | | |
| | | % | 32.1 | 71.0 | 0 | 0 | 39 | | |
| | Quite important | N | 10 | 3 | 0 | 0 | 13 | | |
| | | % | 18.9 | 9.7 | 0 | 0 | 13 | | |
| Somewhat important | | N | 9 | 0 | 0 | 0 | 9 | 0.01* | 45.72 |
| | | % | 17 | 0 | 0 | 0 | 9 | | |
| | Unimportant | N | 0 | 0 | 0 | 0 | 0 | | |
| | | % | 0 | 0 | 0 | 0 | 0 | | |
| | Extremely important | N | 17 | 21 | 0 | 2 | 40 | | |
| | | % | 32.1 | 67.7 | 0 | 28.6 | 40 | | |
| No hope of good quality of life in future | Very important | N | 22 | 9 | 2 | 2 | 35 | 0.01* | 42.99 |
| | | % | 41.5 | 29 | 22.2 | 28.6 | 35 | | |
| | Quite important | N | 7 | 1 | 7 | 3 | 18 | | |
| | | % | 13.2 | 3.2 | 77.8 | 42.9 | 18 | | |
| | Somewhat important | N | 2 | 0 | 0 | 0 | 2 | | |
| | | % | 3.8 | 0 | 0 | 0 | 2 | | |
| Unimportant | | N | 0 | 0 | 0 | 0 | 0 | 0.01* | 42.99 |
| | | % | 0 | 0 | 0 | 0 | 0 | | |
| | No response | N | 5 | 0 | 0 | 0 | 5 | | |
| | | % | 9.4 | 0 | 0 | 0 | 5 | | |

[Table/Fig-7]: Cross-tabulation of age and factors of decision making.

*significant

In this study, 99/100 were aware of the concept of EOL care but showed no significance statistically. A 59/100 participants were aware about the current laws related to EOL care; 69/100 have heard about living will. This was not in agreement with the research done by Agrawal K et al., where most respondents i.e., 81.7% have heard of EOL; the primary information source being through their work in their respective specialities [17]. In this study there was a significant association between the factors like policies, awareness of current laws, committee/team in their hospital to initiate decision on EOL, special allocated area for patients for grief to ensure necessary privacy, fury experience from patient/attender during practice, hospital consideration towards spiritual, religious and cultural beliefs

in dealing with EOL patients. Majority of the respondents reviewed that in the medical curriculum, adequate training and education for dealing with critically ill patients and their issues related to EOL was "somewhat" (39.1%) or "not at all" (48.5%) present. More than 90% approved or strongly agreed that specific training regarding EOL care ought to be incorporated in the medical curriculum. In a study done by Agrawal K et al., 135 health providers had speciality in anaesthesiology, 36 in critical care, 5 in internal medicine, 3 in neurology, 10 in neurosurgery, 8 in pulmonary medicine and 5 in infectious diseases and mean age was 48±18.1 years. In our study, majority (58) were specialised in critical care out of which 29 aged 25 to 35 years; 20 aged 36 to 45 years, 19 participants were administrators and 23 were specialised in oncology and this was in contrast with the study by Agrawal K et al., where most of the critical care specialists lacked EOL awareness [17]. In present study, 29/100 participants had experienced lack of communication while giving EOL care to patients i.e., 71 % participants were comfortable to discuss the EOL with the patients/family attenders and 66% participants felt that hospitals took into consideration of spiritual, religious and cultural beliefs in dealing with EOL care patients. Whereas Cheung NY et al., conducted a study where most of the participants felt comfortable (80%) to communicate about the EOL care issues with patients and/or their families and a majority of health professionals (21%) were influenced by their religious affiliation [18].

Our study mentions that the factors like age of the patient, duration of disease, economic factor, health insurance, patient suffering, emotional distress among patient/attender and no hope of good quality of life in future with age plays a vital role in the life of patients who are in EOL care. However, Wright AA et al., reported considerable correlation with increased emotional distress or psychiatric disorders. Their results revealed that EOL care discussions might have great advantage for patients and their caregivers [19].

Different palliative care projects, investigate in different nations and medical services frameworks show that they can improve subject results, incorporating personal satisfaction and indication control, and results of guardians, similar to stretch decrease and broken misery. Additionally, most research findings demonstrate at least cost neutrality, with others showing considerable cost avoidance by shifting care to locations that the subjects prefer from the acute care settings i.e., in residential hospice or at home [20]. According to Pham B and Krahn M, it is estimated that the yearly expense of delivering care in their last year of life accounts for around 9% of the Ontario health care budget. Access to integrated, total support and pain/symptom management seems to be unbalanced and inadequate and financial status plays a major role in EOL patients [21]. A study conducted by Hidaka T et al., concluded that elderly people's low subjective economic status might lead to lack of EOL conversation experience with their families and friends, hampering elderly people from sharing and understanding preferences of EOL [22]. In our study, chi-square test revealed considerable relation between all the factors of barriers viz., laws, fear of litigation, hospital policies and ethical concerns, cultural and religious factors, external factor (influence of others) with age. Spirituality and religion are very vital to EOL's subject and family experience. During the clinical experience doctor's attitudes to spiritual and religious matters have been shown to differ with their own religious and spiritual characteristics [23,24]. In the literature, various types of barriers of EOL have been reported by various authors. According to Stewart H et al., the highest rated barriers of EOL were: 1) Physician reluctance to make referrals; 2) Physician lack of familiarity with availability and suitability of hospice; and 3) Association of hospice with death [25]. There are numerous other suggestions derived from the literature on barriers related to hospice care, including: 1) Misconceptions of hospice as a place, rather than a model of care; 2) Late patient referrals to hospice; 3) Belief that hospice connotes death and giving up; 4) Impression on

the part of hospices that they are excluded from regulatory scrutiny; 5) Poor communication with health plan administrators, physicians, or case managers by hospice; 6) Lack of consistent standards among hospices as to whom they accept and when they accept; 7) Inappropriate discussion with family members and patients about payment or coverage, matters rightly concerning hospice and the Health Medical Organisation (HMO); 8) Some hospices viewed as being more inclined to accept cancer patients than those with other conditions; 9) Lack of consistent data collection and reporting; 10) Lack of competency standards; 11) Belief that referral to hospice destroys hope for the patient; 12) Belief that referral to hospice represents failure by healthcare provider; 13) Lack of education of healthcare professionals on hospice admissions criteria and services available; and 14) Healthcare professional's fear of losing control of the patient once the patient is referred to hospice [26]. In summary, future suggestions are needed to inspire nurses and other providers of healthcare to enhance an individual's care facing EOL.

Limitation(s)

This study was conducted for only three months duration in Bengaluru with a limited sample size which was available in this part of the region. So, there is a huge scope for future research if it is conducted as a multicentric study on larger patients in different regions. This will augment to find out more evidences on this research.

CONCLUSION(S)

This study revealed that improvements in rules and regulations and increase in awareness among stake holders who are involved in EOL care are much needed that reflect EOL persons' health needs and circumstances. Along with that, further steps are required to enhance the quality of care, which can have the potential to increase equity in the EOL care system.

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Q1-Are you aware of the concept of EOL?

Q2-Are you aware about the current laws related to EOL care?

Q3-Have you heard about living will?

Q4-Do you have a policy on EOL in your hospital?

Q5-Do you have a committee/team in your hospital to initiate or take decision on EOL care?

Q6-Is the staff in your hospital being educated and trained on EOL care?

Q7-Does your hospital have special allocated area for these patients for grief to ensure necessary privacy?

Q8-Have you experienced lack of communication while giving EOL patient (like family member not understanding the condition of patient, communication gap among hospital team providing care)?

Q9-If yes how to overcome such issue?

Q10-While dealing with EOL patient have you experienced fury from patient/attender during your practice?

Q11-If yes what is the probable cause of the fury?

Q12-Does the hospital take into consideration spiritual, religious and cultural belief in dealing with EOL care patients?

Q13-Does the hospital provide any special support for patient/attender during EOL (e.g., clinical psychologist)?

Q14-During EOL how important are these factors to you in decision making:

Age of patient

Duration of disease

Economic factor

Health insurance

Patient suffering

Emotional distress among patient/attender

No hope of good quality of life in future

Q15-How do you rate the following as the barrier of good EOL in your hospital?

Laws

Fear of litigation

Hospital policies

Ethical concerns

Cultural and religion factor

External factor (influence of others)

Others (please mention).