



## HEALTHCARE PROFESSIONALS -KNOWLEDGE ABOUT END OF LIFE CARE

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### Abstract

**Background & Objectives:** End of life care is care provided to patients who are nearing death with no more hope to survive meaningfully and are emotionally and physically experiencing a distressing situation. The main aim is to describe the knowledge about end of life care issues among health care professionals.

**Research Design & Samples:** The study is descriptive, sample size is 200 and the respondents are chosen from the hospitals that gave consent to undertake the study and the respondents are Doctors, Nurses and Social workers having experience in the area of end of life care.

**Tools Used:** Self structured Questionnaire was used for the purpose of assessing the knowledge of the respondents. The study results will enhance understanding of the knowledge of health care professionals in end of life and thereby enable health professionals to address end of life concerns effectively.

**Keywords:** End of Life, Knowledge, Health care professionals.

### Introduction

End of life care includes medical, physical, social and psychological care given to the ailing patient with an incurable health condition who is approaching his or her end of life and it is also the care and support given to their grieving family members.

When a person is experiencing an incurable illness, palliative care, supportive care and end of life care is expected to keep that ailing person as comfortable as possible by addressing their physical and emotional trauma. End of life care aims at providing a strong and a meaningful support towards the psychological, social and spiritual needs and queries of the immediate family members of the patients. End of life care support is a holistic approach as the 'whole' person is dealt with every aspect of care. Health care professionals play important roles in treating the patients as well as addressing the patients' and the family members challenging queries regarding diagnosis, various treatment options and the prognosis. The attitude and knowledge of the health care professionals in our culture towards providing medical care and support during the end of life of ailing patients are worth studying.

### Need for the Study

India is a country with rich cultural background and people vary in their faith, religion, and language. When it comes to treating their loved ones who are suffering from terminal long term illnesses the family members travel extra miles from north to south and east to west to treat them. Knowing their culture, their perceptions towards various treatment modalities and their expectations and understanding about the disease condition is an important at the same time a challenging task.

There are families in our culture that disclose the diagnosis to their family members who are ailing from terminal illnesses. The families that have open discussions about the illness, treatment and its consequences with the ailing persons in their families are better prepared to face their lives than those who refrain from discussing it. The families that keep the patients at dark about their condition will tremendously burden the family economically and psychologically. Therefore the study focuses on analyzing the attitude and knowledge among health care professionals about end of life care concerns and the results of the study will enhance the health care professionals to understand the psychological concerns of patients and families and assist them to take informed decisions.



### **Scope of the Study**

The researcher's attempt to analyze and describe the knowledge of healthcare professionals about end of life care will provide professional and practical support for health care professionals and help them address end of life care issues with confidence. The study is also expected to leave them empowered with adequate knowledge about common man's expectation towards end of life of their family members on end of life care issues. This will result in empowering the patients and their family members too in taking meaningful decisions during end of life situations.

### **Definition**

End of Life Care refers to "Multidimensional assessment and interventions provided to assist individuals and their families as they approach end of life" (NASW).

### **Review of Literature**

**Stanley C Macaden et al**, in their position paper on "End of Life care policy for the dying: Consensus position statement of Indian association of palliative care(2014) attempted to develop an End of Life Care Policy for patients who are dying with an advanced life limiting illness. The observational studies and key surveys demonstrate that EOLC in India is delivered ineffectively. Limited awareness of EOLC among public and health care providers, lack of EOLC education, absent EOLC policy and ambiguous legal standpoint are identified to be some of the major barriers in effective EOLC delivery.

**SavitaButola (2014, India)** on "Knowledge, attitude and practices regarding palliative care among doctors in Border Security Force" reported that majority of the doctors were not aware of the basic concept and less than half could name a palliative centre. Almost half of the study population believe telling a patient about his / her illness depends on both the patient's and family's wishes. The study concluded stating that creating awareness would be the first step towards integration of palliative care into existing healthcare systems and that a multipronged approach is needed to improve the knowledge, attitude and practices regarding palliative care.

**Ahmad Ayed et.al (2015 Palestine)** on their cross sectional study "The nurses' knowledge and attitude towards Palliative Care" observed that minimum number of the respondents had good overall knowledge about palliative care, half of them had training of palliative care and very less percentage had good attitude towards palliative care. It is identified that there was a significant difference between Nurses' qualification, experience and training of palliative care. The study recommended to give due attention to palliative care by the National Health Policy and that palliative care should be incorporated in the national curriculum of nurses' education.

**Izette Lorraine M Libo (Qatar2017)** in the study on "Oncology nurses' perceptions of end-of-life care in a tertiary cancer centre in Qatar" reported the nurses' perceptions of End of Life care. It is observed that, there was no significant relationship between the participants' profiles and their perceptions of EoL care. However, very few of them had completed educational courses in death and dying. The study findings recommend that nurses have an important impact on EoL care, and continuous education is necessary to improve their confidence when they work with dying patients and their families.

### **Research Methodology**

The study is descriptive in nature that describes the knowledge about end of life care issues among health care professionals. The respondents were selected from hospitals that gave consent to undertake the proposed study. The sample size is 200 and the sampling method adopted is purposive sampling. The tools used to collect data to analyze the respondents' knowledge were constructed by the researcher by doing literature reviews and discussions with professionals in the related field. A pilot study was conducted and necessary modifications were done in the interview schedule, after which the tool was administered.



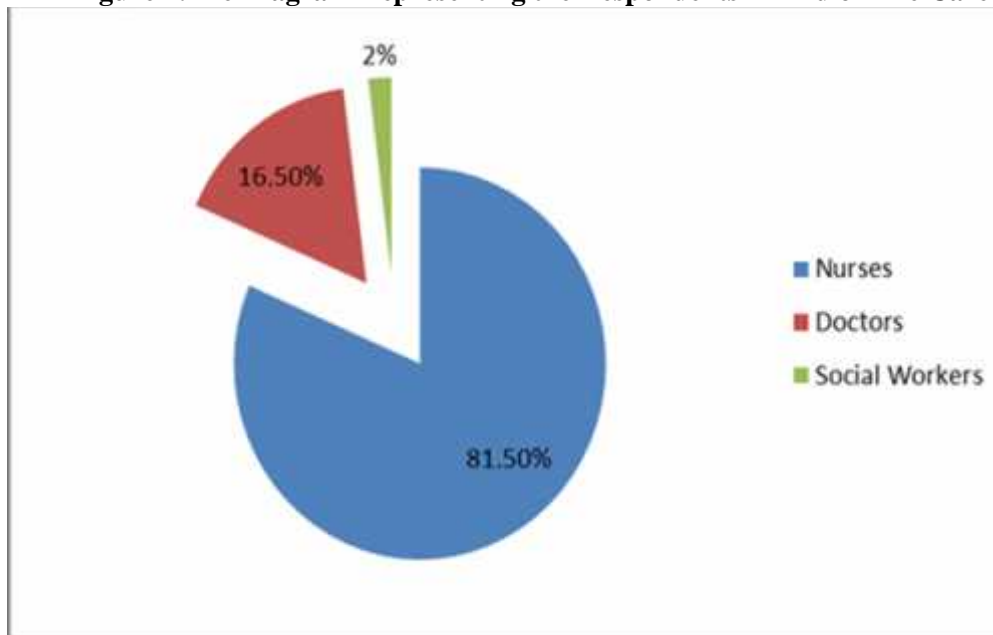
## Findings

1. The mean age of respondents' is 30.24.
2. About (89.5%) of the respondents was women and the rest (10.5%) were men. Among them half (50%) of them were married and (49%) of them were not married as yet and the rest (1%) were divorced.
3. Religion wise distribution indicates that majority (76%) of the respondents was Hindus, (20.5%) were Christians and (3.5%) were Muslims.
4. The source of information regarding end of life for the health care professionals (93%) were through their work experience in health care settings.
5. About half of them (58.5%) have expressed that end of life care and palliative care are the same. About (62.5%) have stated that all patients suffering from terminal illnesses are provided end of life care.

## Discussion

In our study, majority of the respondents belonged to nursing category who had extensive experience of working with terminally ill ailing patients. Similar other studies in the area of end of life care focus on the nurses' knowledge, attitude and perceptions about EOLC. It is a fact that compared to other health professionals nurses are in large number providing service in health care. It is observed in the study that though the respondents' have overall knowledge about end of life, only (7%) were professionally trained in EOLC and the remaining population had acquired knowledge through work experience. In a study by Ahmad Ayed et al (Palestine 2014) they have stated the need to incorporate palliative care in the national curriculum of nurses' education. Similarly it is felt that healthcare professionals need to professionally get trained in initiating discussions about end of life care with patients and their families.

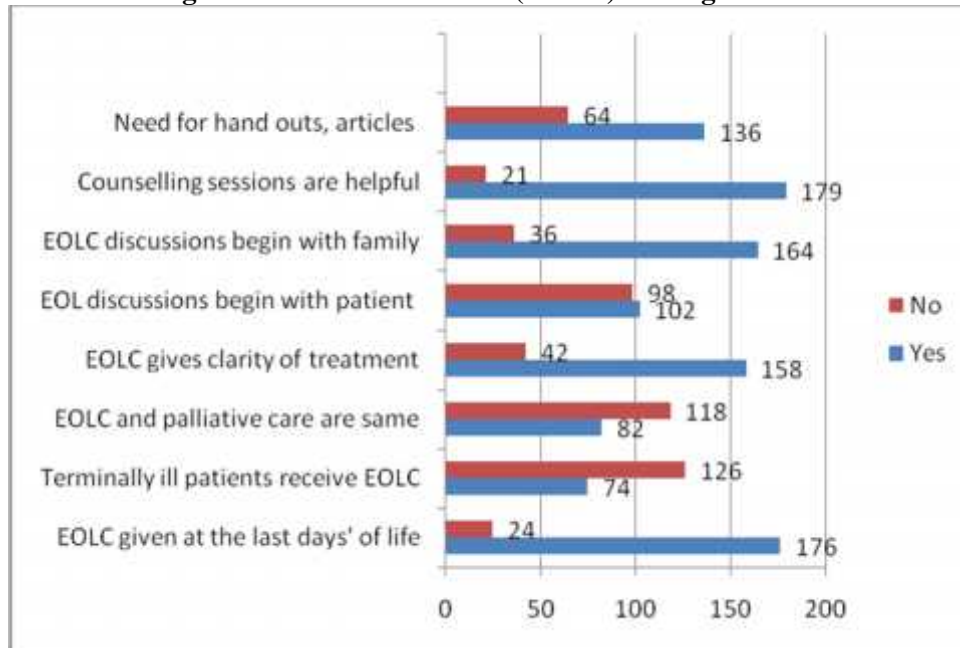
**Figure 1: Pie Diagram Representing the Respondents in End of Life Care**



**Figure 1** depicts that majority (81.5%) of the respondents belong to nursing profession, (16.5%) are Medical Doctors and the rest (2%) of them are Social workers.



**Figure 2: Knowledge about End of Life Care (EOLC) Among Healthcare Professionals**



The results indicate majority of the respondents' (136) feel there is a need for handouts and articles about EOLC to be made available in the hospitals and almost three fourth (179) of them feel counseling sessions are helpful to families.

### Conclusion

The health care professionals provide care for the patients' diseases and infections in the early stages. Once the treating doctor recognizes that he or she can no longer reasonably expect to cure the disease or infection, the attention turns to comfort care for the dying patient. Initiating end of life care discussions is a difficult task for those involved in end of life care. At times these issues are not discussed in detail with the patient or family members and various concerns of the family members can still remain unaddressed. It is important that health care professionals have sufficient knowledge about end of life care. The study is an effort to describe the healthcare professionals' knowledge with regard to end of life care and strives to provide them with insights into the expectations of the patients' family members perspectives and expectations towards end of life situations' of their loved ones.

### References

1. Macaden SC, Salins N, Muckaden M, Kulkarni P, Joad A, Nirabhawane V, et al. End of life care policy for the dying: Consensus position statement of Indian association of palliative care. *Indian J Palliat Care* 2014; 20:171-81.
2. Ahmad Ayed, Sumaya Sayej, Lubna Harazneh, Imad Fashafsheh, Faeda Eqtaït, Arab American University, *Journal of Education and Practice*, vol.6, No.4, 2015.
3. Savita Butola, "Study on knowledge, attitude and practices regarding palliative care among doctors in Border Security Force: vol 22, Issue 5 (October, 2014), pp.272-279.
4. Izette Lorraine M Libo, Abdulqadir J Nashwan, National Center for Cancer Care and Research (NCCCR), Hamad Medical Corporation, Qatar : <https://doi.org/10.12968/ijpn.2017.23.2.66>