SciMedCentral

Annals of Nursing and Practice

Research Article

# End-of-Life Care Education Needs of Nurses: A Cross-Sectional Study

**Gladys Machira*, Irene Mageto and James Mwaura**

*School of Nursing, University of Nairobi, Kenya*

***Corresponding author**
Gladys Machira, School of Nursing, University of Nairobi, Nairobi, Kenya, Email:glawamac@gmail.com

**Submitted:** 06 March 2020

**Accepted:** 30 March 2020

**Published:** 31 March 2020

**ISSN:** 2379-9501



**Keywords**
- Nursing
- End-of-life
- Nurses
- Education

**Abstract**

**Background:** Provision of good quality end-of-life nursing care (EOLNC) is the professional responsibility of nurses. Therefore, educating nurses about EOLNC is a priority in health care settings. Aim: This study sought to assess nurses' perceived education needs regarding provision of EOLNC to patients. Methods: The study surveyed nurses from 8 specialized care units (SCUs; N=174) in one of the national referral hospitals in Kenya. The response rate was 91.1%. Quantitative data analysis was descriptive and co relational while qualitative data was categorized into themes and coded into quantitative data. Findings: Data analysis revealed that the basic nursing education program was inadequate in preparation of nurses to provide EOLNC. Conclusion: The results provide direction for development of EOLNC education programs for Kenyan nurses.

## ABBREVIATIONS

EOL: End-of-Life; EOLNC: End-of-Life Nursing Care; NCK: Nursing Council of Kenya; ELNEC: End-of-Life Nursing Education Consortium; UNHCR: United Nations High Commissioner for Refugees

## INTRODUCTION

End of Life Nursing Care (EOLNC) education is an imperative fragment of the educational experience for nurses in specialized care units. Given the huge number of deaths that is estimated to be 55.8 million globally [1] nurses are expected to provide high-quality EOLNC. However, barriers such as lack of experience when communicating with patients and their families on EOL matters have been reported by nurses [2,3]. The said barriers were reported to have resulted due to inadequate training [4].

Additionally, the absence of training and support for coping with patient death [5] was also highlighted as a barrier by nurses. Condon et al, indicated that this is likely to have occurred due to the fact that views and beliefs surrounding EOL and beyond are overwhelmingly distinctive individually. Moreover, they noted that views and beliefs surrounding EOL are habitually related more to experience than actual teaching.

Nurses are the frontline caregivers for those nearing the EOL [6] and their professional sovereignty is critical in the care at EOL [7] Nevertheless, shortfalls are apparent in the professional and continuing education of nurses [8]. Findings from a systematic review on training courses in EOL care indicated that deficiencies existed in aspects of EOL care especially in communication, symptom management, psychosocial care, and working with families [9].

EOL experiences are unique [10] most people can clearly recall the feelings they had during those times. However, the beliefs of teaching staff arising from those unique experiences can change the attitude and meaning of what students are actually taught [5]. Dillard and Siktberg see Condon et al, [5] observed that teaching staff may be unaware of what students learn through their expressions, priorities and interaction with them, but students are very aware of this; and these gestures from the faculty craft a more lasting impact on the students than what is actually taught.

The implications of these sentiments shed light to the fact that there is need for education regarding EOL and the care involved. Opinions as to what ought to be included in this EOL education may differ among schools of nursing as well as among faculty within the same training institution [4] Such disparities in beliefs could unintentionally surface as hidden curriculum [5].

This therefore, is an indication that much still needs to be done to equip educators with EOLNC competencies which can then be transferred to students [11] The need for training on EOL care was supported by yet another different study that was conducted among novice nurses to explore their experiences with EOL care especially in the area of communication with children [6]. EOL care education was not only wanting in the nursing field alone but also in the medical field [12].

This was documented in a study that was conducted on resident physicians attached to an intensive care unit. The study observed that the residents had inadequate EOL skills at the point of entry, however, they gained the skills through progressive experiences [13]. As such, the study highlighted the importance of role modelling within clinical setting for EOLC skills, and increasing formal EOLC teaching throughout the medical education system. Formal training in EOLNC is not a new concept.

This concept is well documented by End-of-Life Nursing Education Consortium (ELNEC). ELNEC, is an example of what is being done towards improving quality of EOLNC through formal training. It is a national initiative in the United States of America to improve education about EOL care [4]. The didactic content contained in ELNEC was developed by palliative care experts and it regularly undergoes review and update by an advisory panel. ELNEC is an education program that consists of eight basic components: nursing care at the EOL, preparation for and care at the time of death, pain management, symptom management, communication, cultural considerations in EOL care, ethical/ legal issues, grief, loss and bereavement [4].

It is therefore very critical for both new and experienced nurses to be comfortable providing EOL nursing care. Conversely, few nurses have the essential education or experience to deliver optimal EOLC to patients and their families [14] This may be due to the fact that nursing curricula are deficient in didactic content on EOL [4,5]. As was observed by implementing ELNEC, training programs have helped to educate nursing workforce on EOL care concepts [4]. Therefore, it is vital that beside classroom-based education, hospital-based EOL programs be initiated to promote patient-centered care to address the barriers that nurses face while providing EOLNC [15].

In Kenya, a program such as ELNEC does not exist. However, the basic nursing programs in Kenya namely certificate, diploma, and bachelors have some content containing palliative care concepts within which EOLNC concepts are introduced. Moreover, in the year 2013, the Nursing Council of Kenya (NCK) approved a post-basic training in palliative care nursing which has concepts in EOL nursing care. The course is allocated theory and practical hours which are 680 and 1440 respectively. Of the 2120 hours allocated for this program, EOL content is allocated 10 hours (0.5%). Finally, in the year 2014, NCK integrated 45 hours (1.5%) of palliative care content into the undergraduate nursing curriculum.

Nevertheless, a standardized guideline to training institutions regarding the implementation of the integration of the EOL nursing care concepts does not exist. Therefore, despite the fact that the course is there in all the three basic nursing programmes, every institution individually implements the delivery of the content which lacks standardization especially on what is taught regarding EOLNC. As such, much still needs to be done to harmonize EOLNC content across all nursing training institutions in Kenya. Finally, there is need for a critical mass in EOLNC in Kenya and a structured EOLNC program if high-quality EOLNC is to be realized. This study therefore investigated the EOLNC education needs for nurses in selected specialized care units in Kenya.

## MATERIALS AND METHODS

### Design

Cross-sectional study design was used to understand the prevailing characteristics of Kenyan nurses working in specialized care units regarding their perceived EOL education needs. Therefore, it was imperative that data gathered was measurable and objective. This design was considered fit to enhance the achievement of the study objective which was to understand nurses' perceived EOL education needs. Survey was used to gather data from the participants.

### Study site

The study was conducted in one of the national referral hospitals in Kenya which is a major training facility for health care personnel in various disciplines at various levels of training ranging from certificate to post-graduate levels. As such, it attends to a very high number of patients with life limiting illnesses that require end of life nursing care (EOLNC) and the nurses working in the hospital are experienced in providing care to patients in various units of specialization. Specifically, the study was undertaken in eight (8) Specialized Care Units (SCUs). This included: Intensive Care Unit (ICU), High Dependence Unit (HDU), Burns Unit, Renal Unit, Oncology ward, Accident & Emergency Department, Palliative Care department and Oncology clinic.

### Sample

Purposive sampling was used to identify the SCUs while simple random sampling was conducted in each SCU where a total of 174 nurses from the population of 381 were recruited. The inclusion criteria were: a) one was required to be a nurse; b) working in either of the SCUs; c) must have been registered by the Nursing Council of Kenya (NCK); and d) must be in possession of a valid practice license from the NCK.

### Ethical considerations

Approval to conduct the study was gotten from the National Commission for Science, Technology and Innovations (NACOSTI) and Kenyatta National Hospital/ University of Nairobi Ethics and Research Committee (KNH/UON-ERC). Additionally, a written consent was obtained from all the participants. The respondents who met the inclusion criteria were notified that their participation was voluntary and that they were free to withdraw from the study at will. The questionnaires were coded and the respondents were not required to indicate their names or any other form of identification. Information provided was treated with utmost confidentiality and the respondents were made aware of this.

### Data collection

Survey was used to gather data from the participants and a self-administered questionnaire was utilized. The questionnaire was developed solely for this study. It was constituted of both closed and open-ended questions. The questionnaire had three sections on: demographic information; professional information; and items on knowledge on EOLNC. Content and construct validity was established by experts. While face validity was established by the sampled participants during pre-testing as they recognized the type of information being sought.

Cronbach's alpha, was carried out on the nurses' perceived EOL education needs Likert scale comprising 9 items. Cronbach's alpha is a coefficient that measures the correlation between the answers in a questionnaire through the analysis of the profile of the answers given by the respondents, whose values vary from 0 to 1 [16]. Results showed the scale to reach acceptable reliability (α=0.92). Most items appeared to be worthy of retention, resulting in a decrease in the alpha if deleted.

In order to ensure a high response rate, the lead researcher visited the hospital a week before commencement of data collection in order to brief the nurses on the upcoming study. A week after the briefing, each participant got a set of documents comprising of a cover letter, consent form, and questionnaire. A total of 191 nurses were given the set of documents. It took 20 - 25 minutes to complete the questionnaire.

The completed questionnaire was then dropped in the designated box within the unit and was collected by the researcher on alternate days. A total of 174 questionnaires were completed and returned. The filled questionnaires were assessed for completeness and coded for data entry into the computer. All the data gathered was stored under lock and key. The data collection period took four weeks.

### Data analysis and presentation

The data from the questionnaires was checked for accuracy and outliers; then organized, coded, and converted into quantitative summary reports for analysis using the Statistical Package for Social Sciences (SPSS, statistics 24) database. Data gathered was analyzed using descriptive statistics and presented using tables. Cross-tabulation was conducted to establish whether a relationship existed between work station and nurses' perceived EOLNC education needs. Further, inferential statistics, namely Pearson chi square test, was conducted to assess for relationship between the overall EOL care content and the sub-dimensions in the EOL care content. The statistical value was set at p value of 0.05 or less.

### Study limitations

Generalization of this study is limited to nursing professionals who work in large, academic, health care settings. Response rates varied among nursing units, and those who responded to the survey may have been more likely to be interested in EOL care. The self-report method considered in this study could have resulted in reporting bias. Moreover, the survey instrument did not measure actual EOL care education needs but, rather, perceived education needs.

## RESULTS

Of the 191 respondents who were issued with the questionnaire, 174 completed and returned the questionnaire yielding a response rate of 91.1%. The female comprised 52.4% (n=88) and some 31.4% (n=54) had practiced nursing for between 5.5 to 10 years with an average of 11.85 years. 87.5% of the respondents indicated that they cared for a dying patient while they were students. Majority (92.3%; n=156) of the sample unit were of the opinion that it is very important for EOLC content to be included in basic nursing education program with a minority (1.2%; n=2) noting that it was not important. Results suggest that majority of the respondents (87.5%) cared for a dying patient while in nursing school (student) whereas a minority (12.5%) had a contrary opinion.

Respondents when probed to provide their views on the adequacy of basic nursing education program on different aspects of EOL care as indicated in table 1, they had the following responses: 42.1% (n=72) noted that content on " goals of EOLC" was not adequate; 40.7% (n=68) were of the opinion that content on "pain management at the end-of-life" was not adequate; 42.6% (n=72) indicated that content on "other symptoms management (i.e. dyspnea restlessness)" was somewhat adequate; and 47.9% (n=81) found content on communication with patients/families at EOL to be somewhat adequate.

As shown in table 1, the sample unit was divided in their opinions on the adequacy of "role/needs of family caregiver in end-of-life care" content in the basic nursing program with 40.6% (n=69) rating the basic nursing program as not adequate, whereas 40.6% (n=69) rated it to be somewhat adequate. 42.6% (n=72) deemed content on "the care of patients at time of death" to be somewhat adequate; 47.9% (n=81) found "ethical issues in end-of-life care" content not to be adequate; and finally, 44.7% (n=76) of the respondents found "overall content on end-of-life care" not to be adequate. Findings as shown in table 1, indicated that the basic nursing education program in Kenya is not adequate in preparing nurses for provision of EOLNC.

A chi square test for independence was conducted to evaluate whether there are correlations among participants' perception of overall content in EOL care (table 1; item 9) versus the sub-dimensions' of EOL care content (table 1; items 1-8). Overall content in EOL care and sub-dimensions of EOL care content are not related (Pearson chi square test, p=0.000). Thus there was no association in the scoring of the EOL care content by the participants.

In conclusion, regarding the adequacy of the basic nursing education program in preparation of nurses to provide EOLNC, most of the items investigated were not adequately covered. Only one item on "Other symptoms management (i.e. dyspnea, restlessness)" was noted to be adequately covered in the basic nursing program as 33.7% of the respondents rated the content to be very adequate. The lack of association between overall content of EOL care and the sub-dimensions of EOL care content indicated that there is more that would contribute to the overall EOL care content other than the 8 items that were evaluated for this study.

To establish if there was a relationship between work station and nurses' perceived education needs for EOLNC, cross tabulation was done. From the results, most respondents indicated that the basic nursing education program somewhat covered knowledge content on EOLNC. Precisely, 66.7% (n=4) of all the respondents working in the oncology clinic indicated that the content was somewhat adequate (Table 2). Adequacy of the EOLNC knowledge content in the basic nursing education program was also notedto be somewhat adequate by respondents working in renal unit (65%; n=13); ICU (63.1%; n=41); oncology ward (44.4%; n=4); HDU (50%; n=3); and burns unit (52.9%; n=9) (Table 2). This implied that the respondents from the above

**Table 1:** Adequacy of the basic nursing education program on EOLNC content.

| Item | EOLNC content in the basic nursing education program | Ratings (%) | | | |
|---|---|---|---|---|---|
| | | Not Adequate | Somewhat Adequate | Adequate | N |
| 1. | Goals of EOLC | 72(42.1%) | 69(40.4%) | 30(17.5%) | 171 |
| 2. | Pain management at the EOL | 68(40.7%) | 60(35.9%) | 39(23.4%) | 167 |
| 3. | Other symptoms management | 40(23.7%) | 72(42.6%) | 57(33.7%) | 169 |
| 4. | Communication with patients/families at EOL | 51(36.1%) | 81(47.9%) | 27(16%) | 169 |
| 5. | Role of family caregiver in EOLC | 69(40.6%) | 69(40.6%) | 32(18.8%) | 170 |
| 6. | Care of patients at time of death. | 60(35.5%) | 72(42.6%) | 37(21.9%) | 169 |
| 7. | Ethical issues in EOL care | 81(47.9%) | 63(37.3%) | 25(14.8%) | 169 |
| 8. | Overall content on EOL care | 76(44.7%) | 67(39.4%) | 27(15.9%) | 170 |

**PC:** Palliative care; **EOL:** End-of-Life; **EOLC:** End-of-Life Care

**Table 2:** Self-perceived End-of-Life Care Education needs according to setting.

| Setting | Adequacy of basic nursing program regarding EOL content | | | |
|---|---|---|---|---|
| | Not Adequate | Somewhat Adequate | Adequate | N |
| Intensive Care Unit | 11(16.9%) | 41(63.1%) | 13(20%) | 65 |
| High Dependency Unit | 2(33.3%) | 3(50%) | 1(16.7%) | 6 |
| Renal Unit | 1(5%) | 13(65%) | 6(30%) | 20 |
| Oncology Ward | 2(22.2%) | 4(44.4%) | 3(33.3%) | 9 |
| Accident & Emergency | 31(72.1%) | 11(25.6%) | 1(2.3%) | 43 |
| Oncology Clinic | 0(0%) | 4(66.7%) | 2(33.3%) | 6 |
| Palliative Care Department | 3(75%) | 0(0%) | 1(25%) | 4 |
| Burns Unit | 8(47.1%) | 9(52.9%) | 0(0%) | 17 |

EOL: End-of-Life

departments were rather uncertain of what constitutes EOL care content and thus scored a neutral position.

However, this was not the case for respondents who work in palliative care department as 75% (n=3) of them indicated that the EOLNC knowledge content in the basic nursing education program was not adequately covered. The same was reported by 72.1% (n=31) of respondents working in the accident and emergency department. This indicated that the respondents from the two units were conversant with what constitutes EOL care content and they confidently indicated that the content covered in the basic nursing education programmes was not adequate. Hence, from table 2 below, results revealed that majority of the participants observed that the basic nursing education program somewhat covered content regarding EOLNC. Scoring pattern among the different units was also examined.

From the results, there was no particular pattern of scoring by the respondents from the different work stations. Hence, it can be concluded that work station was not related to scoring pattern regarding education needs on EOLNC as most of the respondents irrespective of the work station indicated that the basic nursing education program either did not or somewhat covered content on EOLNC. Nevertheless, the differences in scoring pattern between respondents from different work stations and nurses' perceived EOLNC education needs was not examined for statistical significance as this was not the objective of the current study.

## DISCUSSION

Regarding the adequacy of basic nursing education program in preparation of nurses to provide EOLNC, results indicated that most items in the knowledge dimension were inadequately covered in the basic nursing education program. The inadequacy of EOL care content in the basic nursing education program, was also documented by Montagnini and colleagues [17] in their study on what nurses perceived to be EOL care competencies. Additionally, the gap that exists in the basic nursing program as far as EOLNC content is concerned was also recorded in a different study by Glover et al, [4].

In this study, among the 8 items scored for adequacy of EOLC content in the basic nursing education program only one item (3) of the eight items had favorable score by some of the participants (33.7%) the item on "Other symptoms management (i.e. dyspnea, restlessness)". The favorable scoring for this item could be attributed to the fact that content pertaining to this item may have been covered in the basic nursing education program under the general management of patients.

Interestingly, the deficit in EOL care content in the basic training curricula was not only limited to nurses. Sinha et al, [18] noted that the medical curriculum did not adequately emphasize EOL care and the role of support services e.g., hospice, and interprofessional collaboration. Findings from that study highlighted the need and importance of interprofessional education as a vehicle to provision of safe and high-quality EOLC.

Many factors may be attributed to the existing gap as far as EOLNC knowledge in basic nursing program is concerned. For instance, the beliefs of teaching staff arising from EOL experiences which are unique to each individual can change the attitude and meaning of what students are actually taught [5]. Dillard and Siktberg (see Condon et al, 2013) observed that teaching staff may be uninformed of what students learn through their expressions, priorities and interaction with them but students are very cognizant of this; and these gestures from the faculty craft a more lasting impact on the students than what is actually taught.

Moreover, the presence of some knowledge demonstrated by some of the respondents in this study may highlight the aspect of experiential learning as it can be implied that the knowledge that the respondents demonstrated to possess may have been acquired during practice [14]. As such, there is need for critical mass for nurses specializing in EOLNC and structured education regarding EOL and the care involved [18] as it has been demonstrated that learning also occurs during practice. This is so because, in the year 2014, Goel and colleagues observed that people suffering from life-threatening illnesses have numerous technological advances obtainable to them to elongate and support their life. These technological advances change from time to time and hence the need for nurses to remain abreast [19].

Finally, results showed that majority of the sample (92.3%; n=156) emphasized on the importance of enhancement of the EOLC content in the basic nursing education program. This is so because students take care of dying patients during their study period as was confirmed in this study by 87.5% of the respondents. Moreover, nurses are the frontline caregivers for those nearing the EOL [6]. As such, patients and/or their families expect to obtain expert EOLC characterized by good symptom management, physical care, and integrated care all of which will require a nurse who is well versed with EOL care competencies.

## CONCLUSION

The results of this study are specific to the authors' institution but were congruent with what has been reported in the literature. Next step is planning focused education that will actualize these prioritized core competencies. However, a baseline needs assessment should be completed to identify unique needs for each unit prior to implementing an end-of-life care education program. Teachers also need to develop effective pedagogical methods to use when presenting these competencies to registered nurses. This may be done by use of active learning strategies, e.g., simulation and role playing.

Besides learning knowledge and skills, attitudes too are learned. Assessment of these competencies in nursing education programs will be vital to prospective EOLNC education efforts geared towards improving patient/client outcomes. Growing educational initiatives and developing instruments that emphasize on interprofessional collaboration may help nurses to comprehend the roles and perceptions of other HCPs in provision of EOLC. Hence, the methodology to EOL decision-making will be coherent as well as coordinated.

## REFERENCES


1. UNHCR. UNHCR Global Report. UNHCR Global Focus. 2016.
2. McConnell T, Scott D, Porter S. Healthcare Staff's experience in providing end-of-life care to children: A mixed-method review. Palliat Med. 2016; 30: 905-919.
3. Young A, Froggat K, Brearley S. 'Powerlesness' or 'doing the right thing' - Moral distress among nursing home staff caring for residents at the end of life: An interpretive descriptive study. Palliat Med. 2017; 31: 1-8.
4. Glover TL, Garvan C, Nealis RM, Citty SW, Derrico DJ. Improving End-of-Life Care knowledge among Senior Baccalaureate Nursing Students. Am J Hosp Palliat Med. 2017; 34: 1-8.
5. Condon B, Grimsley C, Kelley T, Nissen M. End of Life and Beyond as Hidden Curriculum. Nurs Sci Q. 2013; 27: 23-28.
6. Hendricks-Ferguson VL, Sawin KJ, Montgomery K, Phillips Salimi CR, Haase JE. Novice nurses' experiences with Palliative and End-of-life communication. J Pediatr Oncol Nurs. 2015; 32: 240-252.
7. Paganini MC, Bousso RS. Nurses' Autonomy in end-of-life Situations in Intensive Care Units. Nursing Ethics. 2015; 803-814.
8. Nedjat-Haeim FR, Carrion IV, Gonzalez K, Ell K, Thomson B, Mishra SI. Exploring Health Care Providers' Views About Initiating End-of-Life Care Communication. Am J Hosp Palliat Med. 2016; 308-317.
9. Pulsford D, Jackson G, O'Brien T, Yates S, Duxbury J. Classroom-based and distance learning education and training courses in end-of-life care of health and social care staff: A systematic review. Palliat. Med. 2013; 27: 221-235.
10. Cain CL, McCleskey S. Expanded definitions of the "good death"? Race, ethnicity, and medical aid in dying. Sociology of Health & Illness. 2019; 41: 1175-1191.
11. Connolly KK, Blanchette PL, Oue D, Izutsu S. Education and End-of-Life Options: Hawaii's Our Care, Our Choice Act. Hawai'i Journal of Health & Social Welfare. 2019; 78: 236-239.
12. Agrawal K, Garg R, Bhatnagar S. Knowledge and Awareness of End-of-life Care among Doctors Working in Intensive Care Units at a Tertiary Care Center: A Questionnaire-based Study. Indian Journal of Critical Care Medicine: Peer-Reviewed, Official Publication of Indian Society of Critical Care Medicine. 2019; 23: 568-573.
13. Chen E, McCann JJ, Lateef OB. Attitudes Toward and Experiences in End-of-life Care Education in the Intensive Care Unit: A survey of Resident Physicians. Am J Hosp Palliat Med. 2015; 738-744.
14. Abate AT, Amdie FZ, Bayu NH, Gebeyehu D, G/Mariam T. Knowledge, attitude and associated factors towards end of life care among nurses' working in Amhara Referral Hospitals, Northwest Ethiopia: A cross-sectional study. BMC Research Notes. 2019: 12.

15. Hu Y, Jiao M, Li F. Effectiveness of spiritual care training to enhance spiritual health and spiritual care competency among oncology nurses. BMC Palliative Care. 2019; 18.

16. Maltby J, Day L, Williams G. Introduction to Statistics for Nurses. Harlow: Pearson Education Limited. 2007.

17. Montagnini M, Smith H, Balistrieri T. Assessment of Self-Perceived End-of-Life Care Competencies of Intensive Care Unit Providers. Journal of Palliat Med. 2012; 15: 29-36.

18. Sinha P, Murphy SP, Becker CM, Poarch HJ, Gade KE, Wolf AT, et al. A novel interprofessional approach to end-of-life care education: A pilot study. J Interpr of Care. 2015; 29: 643-645.

19. Goel A, Chhabra G, Weijma R, Salori M, Thornton S, Achondo B, et al. End-of-Life Care Attitudes, Values, and Practices Among Health Care Workers. Am. J Hosp Palliat Med. 2014; 31: 139-147.

**Cite this article**

*Machira G, Mageto I, Mwaura J (2020) End-of-Life Care Education Needs of Nurses: A Cross-Sectional Study. Ann Nurs Pract 7(1): 1109.*