**Doctors’ Training and Knowledge in End of Life Care: Case Study of Three Mission Hospitals in Kenya**

**Abstract:** There is an increasing number of people in Kenya with life limiting illnesses who require palliative and end of life care. In developed countries such care is often given in a hospice or at home by palliative service professionals. In Kenya, there are limited such resources and therefore this care frequently ends up being offered by inpatient healthcare professionals spear-headed by doctors. To assess doctors’ previous training and current knowledge in end of life care, a descriptive cross-sectional survey utilizing a questionnaire was administered to doctors working in three mission hospitals in Kenya. Nearly half of the doctors had never received any form of undergraduate training in end of life care. Those clinicians who had received more intensive end of life care training appeared to have a greater knowledge of end of life care management. Curriculum reviewers should incorporate end of life care as part of training for all doctors.

**Keywords:** end of life care (EoLC), palliative care (PC), training, knowledge

1. **Introduction**

Palliative care as defined by WHO is “an approach that seeks to improve the quality of life of patients and their families facing the problems associated with life-threatening illness” (WHO, 2002). The estimated global number of adults in need of palliative care at the end of life is over 19 million according to WHO (WHO, 2014). In Sub-Saharan Africa, HIV/AIDS, cancer and cardiovascular diseases are the leading causes of terminal illness (WHO, 2014). In Kenya, cancer causes 7% of total national mortality per year, with an estimated annual incidence of 37,000 cases and annual mortality of more than 28,000 (Ministry of Health, 2017). Among the reported cases of cancer, 80% are diagnosed at advanced stages when very little can be achieved in terms of curative treatment (Ministry of Health, 2017). These statistics underscore the need for palliative and end of life care.

End of life care (EoLC) is part of the spectrum of palliative care and is defined as care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die (National Council for Palliative Care, 2011). Although difficult to predict, end of life care is usually defined as being for individuals who are in the last year of life, and for legal and health care purposes, typically the last six months of life (Krau, 2016).

Patients with advanced terminal illness have common symptoms towards the end of life. A systematic review identified eleven common symptoms among end-stage patients with cancer, AIDS, heart disease, chronic obstructive pulmonary disease, or renal disease (Solano, 2005). These are: pain, depression, anxiety, confusion, fatigue, breathlessness, insomnia, nausea, constipation, diarrhoea, and anorexia (Solano, 2005). Among these symptoms pain, fatigue and breathlessness were the most common in all the five diseases (Solano, 2005). Improving quality of life by controlling these symptoms rather than extending their life is the preference and priority of most patients. (Powell, 2014) Other key priorities identified by patients requiring EoLC are emotional well-being, spiritual care, family support, choice of where to be cared for, and appropriate information provision (Powell, 2014).

Are the hospital-based doctors prepared to care for these patients? A literature review on the training of health-care professionals across Africa in palliative care for cancer patients noted that the number of doctors per head of population is low and the number of doctors with advanced training or knowledge in palliative care is even lower (Rawlinson et al, 2014). The WHO recognizes the challenge this inevitably brings and thus advocates for incorporating palliative care into the services provided by all doctors dealing with cancer patients as well as including it in the undergraduate curriculum (WHO, 2007).

In Kenya, a national palliative care training curriculum for HIV &AIDS, cancer and other life-threatening illnesses was launched in 2013 (Ministry of Health, 2013). In the same year, a higher diploma palliative nursing course was launched in one of the national medical training colleges. There have also been efforts to incorporate palliative care training into undergraduate medical training. A study reviewing the success of these training ventures identified numerous challenges including; few hours allocated for the unit, inadequately prepared clinical staff and limited institutional support (Cheptum, 2016).

Most African studies performed to date have evaluated the knowledge of nurses in palliative care (Fadare, 2014; Kasa, 2014; Machira 2013), but there is paucity of evidence with regards to doctors. The limited evidence to date in an African context implies that doctors have limited knowledge and skills in palliative care (Rawlinson, 2014). Doctors provide a key role in end of life care since they make the diagnosis of a terminal illness, make decisions on patient’s care, prescribe medications, and communicate to the patients and their families. But how prepared are the doctors in offering this crucial service? This current study aimed to determine the training and knowledge of doctors in end of life care.

1. **Statement of the Problem**

There are a growing number of people with incurable illnesses in Kenya due to chronic diseases such as HIV/AIDS, cardiovascular diseases and cancer (Ministry of Health, 2013). Patients who suffer from these illnesses require end of life care as part of their broader palliative care. In the developed countries this care is given in a hospice or at home by palliative service professionals. However, in Kenya, there are limited such resources and opportunities and therefore this care frequently ends up being offered by inpatient healthcare professionals. These professionals are led by doctors. However, there is paucity of literature on doctors’ training and knowledge in offering end of life care in our setting.

1. **Objectives**

The objectives of this study were two-fold: to describe doctors’ previous level of training in end of life care and to assess doctors’ knowledge with regard to end of life care

1. **Literature Review**

*4.1 Doctors’ training in end of life care*

Appraising the existing training models for palliative care is crucial. A literature review conducted in Canada looking at resources for educating, training, and mentoring all physicians providing palliative care discovered that despite there being many resources for palliative care training, very few were in use in physician training (Downar, 2017). It also noted that not much was known about which palliative care educational approaches impacted physician behaviour and patient care (Downar, 2017). A shift from time based (e.g. lecture hours) to competency-based approach in undergraduate and postgraduate medical education were noted as important interventions in palliative training (Downar, 2017).

What is the situation of palliative and end of life care training for doctors in Africa? Championing, advocacy and strengthening of EoLC training and educational opportunities for Doctors has largely been done by non-governmental bodies and associations such as the African Palliative Care Association (Rawlinson, 2014). These organizations have advocated for review of curriculum and provided placements of providers to improve knowledge and skills on EoLC. Availability of training opportunities specifically tailored to doctors lacks in the region and hence their ill-preparedness in the area of EoLC. University of Cape Town in South Africa has a postgraduate palliative care distance education programme for doctors (Ens, 2011). A survey done to assess the programme noted the need to incorporate practical training with patients (Ens, 2011).

In Kenya, there have been initiatives to strengthen palliative care training and improve health professional’s knowledge and skills in matters palliative care. For instance, a national palliative care training curriculum for HIV &AIDS, cancer and other life-threatening illnesses was launched in 2013 (Ministry of Health, 2013). In the same year, a higher diploma palliative nursing course was launched in one of the national medical training colleges. There have also been efforts to incorporate palliative care training in undergraduate medical training.

*4.2 Doctors’ kno**wledge in end of life care.*

Studies exploring doctors’ knowledge in EoLC have demonstrated deficiencies in certain key domains. A cross-sectional study conducted to assess knowledge in palliative terminal cancer care among general practitioners in Thailand reported inadequate knowledge on truth telling, pain management and emergency management (Budkaew, 2013). A similar study conducted in Italy reported deficiencies in knowledge as only 25% could correctly define palliative care, 41% the objectives of palliative care, and 66% that palliative care should be provided by a multi-professional team (Beccaro, 2012). Furthermore, in another similar study from Singapore, only one-fourth of the physicians answered all knowledge questions correctly and statements regarding pain management had the lowest correct responses.

In Africa there is paucity of literature on studies looking at doctors’ knowledge in end of life care. The limited studies done further demonstrate knowledge gaps in this domain. In Nigeria, an interventional study on medical interns’ knowledge of palliative care showed that there was poor knowledge due to ignorance (Nnadi, 2016). The knowledge scores appreciated significantly after an educational intervention (Nnadi, 2016). Another similar study from Nigeria demonstrated insufficient knowledge on the interdisciplinary facet of palliative care (Ker, 2017). Forty-six (40%) of the respondents believed that it was the nurses’ responsibility to provide palliative care services, while 32 (28%) believed it was the doctors’ role (Ker, 2017).

There is much less literature present from a Kenyan context. One study assessing health workers’ knowledge and perception on palliative pain control in Western Kenya revealed a reluctance for clinicians in prescribing morphine to palliative patients due to the fear of addiction, dosing and side effects (Zubairi et al, 2016). Another study explored palliative care provider self-competence among staff in an inpatient hospice setting in Kenya (Sedillo et al, 2015). It found that the three lowest mean self-competence scores among the clinical staff were: discussing inpatient hospice referral, the use of injectable opioid analgesics, and the assessment of pain in the paediatric patient (Sedillo, 2015).

1. **Methodology**

*5.1 Study design, site*

This was a descriptive cross-sectional study conducted in three mission hospitals in Kenya (Kijabe, Tenwek and Chogoria). These hospitals serve as teaching institutions with consultants, surgery residents, family medicine residents, medical officers and undergraduate interns. They also serve as referral facilities, receiving patients from all over the country and a few from across borders. The three mission hospitals have established palliative care units to support patients with life threatening illnesses and as such there was high expectation that EoLC issues would be handled competently.

*5.2 Study population, duration*

This study was conducted as a census study among all doctors involved with adult inpatient care. The three hospitals had a total of 162 doctors who were involved in adult inpatient care. The doctors recruited had to have had a minimum of six months clinical working experience. This was to ensure that knowledge assessed based on actual interaction with end of life patients. Doctors who deal purely with children were excluded from the study (i.e. pediatricians and pediatric surgeons). This is because children are a special population with different end of life care needs which also include their parents or guardians. They therefore would require a separate study. The duration of data collection was two months, May to July 2017.

*5.3 Instrumentation*

The instrument used was a questionnaire. This was designed from two externally validated questionnaires utilized for similar studies (Nakazawa, 2009; Yamamoto, 2013). These questionnaires have also been used as basis for designing questionnaires in other contexts such as Brazil (Zalaf, 2017), China (Gu, 2016), USA (Brock, 2015) and India (Prem, 2012). To ensure relevance, expert opinion from physicians in our setting was sought. The questionnaire was pretested to assess feasibility.

The questionnaire had two sections. The first section had the respondent’s demographics including: age, gender, graduation year from medical school, country of medical school training and level of EoLC training attained. The second section had the knowledge questionnaire with nineteen questions covering seven domains of EoLC: philosophy of palliative care, pain, opioid side effects, dyspnea, psychological distress, delirium and communication. The questions were answered with either ‘True’ or ‘False’ and a high score indicated better knowledge.

*5.4 Data Analysis.*

The results were entered onto Microsoft excel worksheet and analyzed using computer software tool, SPSS version 25. Association of level of training and knowledge scores with respondents’ demographics was tested using independent student t-test. All analysis was carried out at the p<0.05 significant levels. Data was presented in text, tables and figures.

*5.5 Ethical Considerations*

Ethical approval was obtained from the Institution Review Board (IRB) of the university and respective hospitals before embarking on the study. Consent forms were signed by the respondents before taking the questionnaire. The questionnaires were anonymous and upon completion, they were put in a sealed box and retrieved only at the time of analysis

1. **Results**

*6.1 General information*

Out of the target population, 96 respondents filled out and submitted back their questionnaires giving a response rate of 59.2%. The respondent’s demographics are summarised in Table 1.

Table 1- Respondents’ demographics

|  |  |  |  |
| --- | --- | --- | --- |
| Characteristic |  | N | % |
| Age (Years) | ≤ 40 | 76 | 79.17 |
| > 40 | 20 | 20.83 |
|  |  |  |
| Gender | Male | 54 | 56.25 |
| Female | 41 | 42.71 |
|  |  |  |
| Seniority | Junior (medical officer intern, medical officer, resident) | 59 | 61.46 |
| Senior (consultant) | 36 | 37.50 |
|  |  |  |
| Specialty | Medical Specialty  | 25 | 26.04 |
| Surgical specialty  | 35 | 36.46 |
| \*Not specialised | 36 | 37.50 |
|  |  |  |
| Country of Undergraduate Training | Kenya | 56 | 58.33 |
| Africa (other than Kenya) & other developing countries | 14 | 14.58 |
| USA and other developed countries | 26 | 27.08 |
|  |  |  |
| Terminal Disease Patients cared for in last 6 months | None | 3 | 3.13 |
| ≤20 patients | 48 | 50.00 |
| >20 patients | 44 | 45.83 |
|  |  |  |

\*this included the medical officer interns and medical officers who were generalists.

*6.2 Doctors’ level of training in end of life care*

The results of the doctors’ level of training is summarised in Table 2. In terms of undergraduate training, 40% of the doctors had not received EoLC training in their undergraduate curriculum. For those who had received undergraduate training, only 27% of them had received lectures incorporated with bedside tutorials. Half of the respondents (50%) had received further training in PC and/or EoLC after undergraduate.

Table - Respondents' level of training in end of life care (N=96)

|  |  |  |  |
| --- | --- | --- | --- |
| Level of Training |  | N | % |
| Taught PC/EoLC in undergraduate | Yes | 58 | 60.42 |
| No | 38 | 39.58 |
|  |  |  |
| \*Form of undergraduate training | Lectures only | 41 | 73.21 |
| Lectures and Bedside Tutorial  | 15 | 26.79 |
|  |  |  |
| Further training in PC/ EoLC after undergraduate | Yes | 48 | 50.00 |
| No | 48 | 50.00 |
|  |  |  |

PC (palliative care); EoLC (end of life care)

\*Two of the respondents who answered ‘yes’ to having been taught PC/EoLC training in undergraduate did not answer the subsequent question on the form of training.

*6.3 Comparison of level of training with the respondents’ knowledge scores*

Comparison of the level of training with the knowledge scores is summarised in Table 3. There was no significant difference in knowledge scores between those who had been taught EoLC in undergraduate and those who hadn’t (78.11% vs 76.16%, p= 0.422). However, those who had bedside tutorial incorporated with lectures in undergraduate training scored significantly better than their counterparts who had lectures only (85.26% vs 75.63%, p=0.001). The respondents who had also obtained postgraduate EoLC training also scored significantly better than those had hadn’t (79.74% vs 75.00%, p= 0.046).

Table - Comparison of level of training with knowledge scores (N=96, \*p value <0.05)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Level of training |  | N | Knowledge mean score (%) | p value |
| Taught EoLC in undergraduate | Yes | 58 | 78.11 |  |
| No | 38 | 76.16 | 0.422 |
|  |  |  |  |
| Form of undergraduate training | Lectures only | 41 | 75.63 |  |
| Lectures and Bedside Tutorial  | 15 | 85.26 | \*0.001 |
|  |  |  |  |
| Further training in EoLC after undergraduate | Yes | 48 | 79.74 |  |
| No | 48 | 75.00 | \*0.046 |

\*significant p-value

*6.4 Doctors’ knowledge in end of life care*

A summary of the respondents’ knowledge mean scores per question is presented in Table 4,whileFigure 1 shows a summary of the seven domain mean scores. The overall EoLC knowledge mean score for all the respondents was 77.37%. As shown in Figure 1, the doctors were most knowledgeable in the domains of psychological distress (95.75%) and opioid side effects (91.1%) and least knowledgeable in the domains of delirium (64.90%) and dyspnoea (65.20%).

Table 4- Proportion of doctors with correct answers to each of the knowledge questions (N=96)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Domain | True/ False Statement | Answer | No.(Correct) | % (Correct) |
| Philosophy of PC | 1. Palliative care is synonymous with terminal care | F | 71 | 74.0 |
| 2. Palliative care should not be provided along with anti-cancer treatments | F | 90 | 93.8 |
| Pain | 3. One of the goals of pain management is to get a good night’s sleep | T | 85 | 88.5 |
| 4. When cancer pain is severe, one of the opioids is used as an initial analgesic | T | 76 | 79.2 |
| 5. When opioids are initially prescribed, all non-opioid analgesics should be discontinued | F | 87 | 90.6 |
| 6. Morphine is used safely in a patient with renal failure | F | 27 | 28.1 |
| 7. Opioid rotation or switching should be considered when it is difficult to increase the dose of opioids due to adverse effects | T | 87 | 90.6 |
| Opioid side effects | 8. It is necessary to use a laxative together with oral opioids, because most patients who take opioids experience constipation | T | 95 | 99.0 |
| 9. Opioids cause addiction in 0.2% or less of cancer patients under careful monitoring | T | 80 | 83.3 |
| Dyspnoea | 10. Morphine can be used to relieve dyspnoea in cancer patients | T | 62 | 64.6 |
| 11. When opioids are taken on a regular basis, respiratory depression will be common | F | 67 | 69.8 |
| 12. Oxygen saturation levels are correlated with dyspnoea | F | 59 | 61.5 |
| Psychological distress | 13. When a patient has a high level of psychological distress, clinicians are recommended to examine whether the patient has suicidal ideation | T | 91 | 94.8 |
| 14. Anxiolytics can be prescribed for palliative patients with psychological distress | T | 93 | 96.9 |
| Delirium | 15. Delirium occurs due to drugs or physical aetiologies | T | 84 | 87.5 |
| 16. Benzodiazepines are the first line therapy for delirium | F | 40 | 41.7 |
| 17. It is better to make the room pitch black for a patient with delirium, so that he or she can sleep well | F | 63 | 65.6 |
| Communication | 18. When physicians convey bad news, they should ask the patient’s concern and understanding about the disease | T | 95 | 99.0 |
| 19. It is better to repeatedly use the word ‘cancer’ when telling the patient about his or her malignancy | F | 61 | 63.5 |



Figure 1- Knowledge mean scores for the seven domains of End of life care

*6.5 Comparison of knowledge scores with respondent’s demographics*

Comparison of the knowledge scores with the respondent’s demographics is presented in Table 5. There was a significant positive association of knowledge scores with: age more than 40 years, seniority, medical specialty and having trained in a developed country. However, there was no significant association with gender, having been taught EoLC in undergraduate or number of terminal disease patients cared for in the last six months.

Table 5- Comparison of respondents' demographics with knowledge scores (N=96; \*p value <0.05)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Characteristic |  | N | Knowledge mean score (%) | Std. Deviation | p-value |
| Age (Years) | ≤ 40 | 76 | 75.74 | 2.304 |  |
| > 40 | 20 | 83.42 | 1.226 | \*0.008 |
|  |  |  |  |  |
| Gender | Male | 54 | 78.05 | 2.448 |  |
| Female | 41 | 76.11 | 1.832 | 0.420 |
|  |  |  |  |  |
| Seniority | Junior | 59 | 73.42 | 2.129 |  |
| Senior (Consultant) | 36 | 84.53 | 1.472 | \*0.000 |
|  |  |  |  |  |
| Specialty | Medical Specialty | 25 | 84.63 | 1.412 |  |
| Surgical specialty | 35 | 80.00 | 1.568 | \*0.029 |
|  |  |  |  |  |
| Country of undergraduate training | Kenya | 56 | 74.26 | 1.775 |  |
| USA and other developed countries | 26 | 87.26 | 1.172 | \*0.000 |
|  |  |  |  |  |
| Terminal disease patients cared for in 6 months | None | 3 | 70.16 | 1.155 |  |
| ≤20 patients | 48 | 76.74 | 2.491 | 0.396 |
| >20 patients | 44 | 78.58 | 1.910 | 0.456 |

**7. Discussion**

*7.1 Doctors’ level of training in end of life care*

The doctors’ level of training in EoLC was not adequate. In terms of undergraduate training, nearly half had not received EoLC training. Among those who had received the training, only about a third had bed side tutorials incorporated with lectures, while the rest had lectures only. Furthermore, only half of them had pusued further EoLC training after undergraduate.

WHO in 2004 recommended that all governments should incorporate palliative care in training of health workers at all levels (WHO, 2004). However, as reflected in this response, EoLC training is not emphasized in undergraduate training. Furthermore, the training is provided as lectures only while contact with dying patients is limited (Gelband, 2001). Focus of undergraduate training on curative care was noted as a reason why newly qualified doctors were unprepared to care for patients at the end of life in the UK (Gibbins, 2011).

Knowledge mean score for those who had bedside tutorial incorporated with lectures was significantly better than those who had lectures only. This shows that practical experience in EoLC training is vital in reinforcing the knowledge learned in class. In deed a literature review aimed at improving medical graduates’ training in palliative care demonstrated that incorporating both theoretical and clinical EoLC training were more effective in undergraduate training (Head, 2016).

The doctors who had trained in developed countries, mostly from the USA, scored significantly better than their colleagues who had trained in Kenya. This is most likely due to the nature of palliative care training in the West which is more developed than in Kenya. For example, since 2007 the Medical School Palliative Care Education Project in the USA has been offering faculty development to medical schools in developing elective clinical rotations in the last two years of medical school (Head, 2016). In Kenya, a national palliative care training curriculum was launched in 2013 (MOH, 2013). The use and impact of this curriculum in EoLC training in Kenya needs to be studied.

*7.2 Doctors’ knowledge in end of life care*

The two domains with the lowest knowledge scores were delirium and dyspnoea. With regard to delirium, only 42% disagreed that ‘benzodiazepines are the first line therapy for delirium’. In Japan, the same question had only 52% correct response (Yamamoto, 2013). This points to inadequate knowledge in the management of delirium which is a common problem in terminal disease patients (Bush, 2017). Delirium is defined as a disturbance in attention and awareness developing over a short period of time (DSM-5). Prevalence of delirium is reported as 13–42% on admission to inpatient palliative care units, increasing to 88% in the last weeks-hours of life (Bush, 2017). It is a clinical diagnosis that tends to be overlooked or misdiagnosed by health workers (De la Cruz, 2015). This lack of a correct diagnosis of delirium may explain the poor knowledge scores in this domain. To address this gap, delirium assessment tools such as the Memorial Delirium Assessment Scale have been developed (Bush, 2017). These tools should be incorporated in the training of doctors in EoLC.

In the domain of dyspnoea, 38% of the doctors answered that ‘oxygen saturation levels are correlated with dyspnoea’. This is false since dyspnoea is a patient-centred symptom that does not necessarily correlate with findings of hypoxia, hypercarbia, or tachypnoea (Kamal, 2011). Furthermore, 35% of them did not know that ‘morphine can be used to relieve dyspnoea in cancer patients’. Similarly, in the Japan study 33% of the doctors did not know that morphine can be used to relieve dyspnoea (Yamamoto, 2013). One common fear among health workers is that morphine can cause respiratory depression, hence this could explain why many do not know that it can be used to relieve dyspnoea. Opioids reduce dyspnoea by reducing the workload of breathing, and the application of appropriate doses of opioids does not cause respiratory depression (Gallagher, 2010). Dyspnoea, or breathlessness, is a common distressing symptom for end of life patients. Its prevalence ranges from 60-95% especially among patients with COPD and heart disease (Solano, 2006). Lack of knowledge in this critical domain therefore calls for urgent intervention to improve quality of life of these patients.

1. **Recommendations and areas for further study**

*8.1 Recommendations*

1. Curriculum reviewers should incorporate EoLC training in undergraduate and postgraduate medical training for all doctors. The national palliative care training curriculum that was launched in 2013 should be customized for undergraduate training of doctors.
2. End of life care training in undergraduate and postgraduate should incorporate both classroom teachings and practical bedside tutorials. Clinical rotation in a palliative care unit should be incorporated.
3. Doctors should be encouraged and supported to pursue further training in end of life care after undergraduate training.
4. Teaching on end of life care should emphasize the gap in doctors’ knowledge in the domains of delirium and dyspnoea identified in this study.

*8.2 Areas for further research*

1. There is a need to study on the practice of end of life care among doctors. This would be a necessary study since good knowledge in end of life care may not necessarily mean good practice.
2. This study was conducted in three Christian mission hospitals in Kenya with both local and foreign doctors. The findings may not be representative of the situation in Kenya. There is need for a similar study to be done in other Kenyan hospital sites that would be more representative of the country.
3. Studies focussing on management of delirium and dyspnoea in end of life care should be done to explore the knowledge gap in these two domains.
4. **Conclusions**

This study focussed on describing the doctors’ level of training and knowledge in end of life care of patients with life limiting illnesses. Doctors level of training in offering end of life care was inadequate with nearly half of them having not received undergraduate training. For those who had received undergraduate training, the majority of the training was in the form of lectures only. Only half of the respondents had pursued further training in end of life care after undergraduate. Having received both lectures and bedside teaching as an undergraduate as well as undergoing further training in end of life care at postgraduate level associated positively with better knowledge in EoLC.

With regard to their knowledge in end of life care, the doctors had overall good knowledge. The domains of end of life care with the highest knowledge scores were psychological distress and opioid side effects while the lowest scores were in the domains of delirium and dyspnoea. Good knowledge scores were positively associated with: older age, seniority, medical specialty and having trained in a developed country.

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