

What do young doctors know of Palliative Care; how do they expect the concept to work?

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Research note

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Abstract

Objectives Discipline of palliative care is still evolving in developed parts of the world while it remains at an infantile stage in Sri Lanka which has not been formally assessed as of today. We aimed at evaluating the level of palliative care knowledge and opinions among young medical graduates. A descriptive cross-sectional study was carried out among pre-residency medical graduates of Sri Lanka through a social media based on-line survey. The pre-tested questionnaire assessed the level of knowledge on general principles, service organization, clinical management and ethical considerations while it also evaluated their opinions. Results Response rate was 35.8% (n=351). The average score among the respondents was 37.25% (standard deviation (SD) = 11.975). Specific knowledge on "general principles" was adequate (score>=50%) with an average of 62.61%, SD=24.5 while "ethics" was observed to be the area with poorest knowledge (average score=19.55%, SD=22). Average scores for "service organization" and "managerial aspects" were 34.54%, SD=17.6 and 32.26%, SD=22.3 respectively. The majority (>90%) believed that de-novo establishment of hospice, hospital and community-based palliative services would sustainably improve holistic patient care. Measures must be taken to optimize basic palliative care knowledge among the undergraduates in view of achieving Universal Health Coverage in the long term.

Introduction

Palliative care is an approach that aims to improve the quality of life of patients, and their families facing the physical, psychosocial and spiritual problems associated with life-threatening illnesses (1).

Department of Census and Statistics of Sri Lanka declared in 2016 through a press release that over the decade preceding year 2011, life expectancy has risen considerably (2). With the advancement of diagnostic technologies, most terminal diseases are revealed at their prodromal stages, resulting in a rise in the population living with life limiting illnesses. A study conducted in the UK estimated a minimum of 63.03% of all deaths need palliative care (3).

A systematic review of international literature on teaching and learning in palliative care within medical undergraduate curricula pointed out the lack of consistency and fragmentation of teaching in the discipline, owing to lack of efficient inter-departmental collaborations. The importance of devising an integrated curriculum for palliative care with strong emphasis on multidisciplinary approach was recommended (4).

The discipline of palliative care thrives at infancy in Sri Lanka where specialists, and published evidence on the discipline lack. Nevertheless, palliative services are on a gradual incline (5). In such a background it is worthwhile exploring the knowledgeability of young doctors on 'Palliative Medicine' to cater the ever-growing palliative care needs (6). This survey was expected provide valuable information for the academics, healthcare staff and policy makers to align their vision accordingly.

This survey was aimed at evaluation of the knowledge and opinions on palliative care among medical graduates who were awaiting to commence residency in 2017.

Methods

Considering the 1186 candidates who have reportedly faced the MBBS (Bachelor of Medicine, Bachelor of Surgery) examination in the year 2017 in Sri Lanka, the calculated sample size was 291 (for a Confidence Interval of 95% with the Standard Error of Mean set at 5%) (7,8).

A descriptive cross sectional study was designed (#07/17, Ethics Review Committee, Faculty of Medical Sciences, University of Sri Jayewardenepura, Sri Lanka) to evaluate medical professionals graduated during the year 2017 from 8 medical faculties of Sri Lanka. (Kotelawala Defense University had not produced its debut batch by this time.) The undergraduates who have not officially completed the degree (owing to any reason) were excluded.

Assessment

There was no consideration to examine the palliative content in the undergraduate curricula initially, since there are no registered (in University Grants Commission of Sri Lanka) academic departments, relevant specialists or defined academic programmes concerning palliative care in any of the medical schools in the country. The study intended to ascertain the level of knowledge of the current graduates, in the hope that its results will be instrumental in devising an academic programme in the future to address the knowledge gap as appropriate.

An online self-administered questionnaire was generated via Google Forms (9). In the absence of a validated questionnaire specifically devised to assess the level of knowledge on palliative care as of the time, the essential core knowledge was assessed as per the endorsements for undergraduate medical education by the European Association for Palliative Care (2007) (10). The validity of the questionnaire was ensured by content validity and face validity. The questionnaire was developed after an intensive literature search and then it was reviewed by a specialist (foreign) in the field of Palliative care and a local specialist in medical education. Amendments in the questions were made by common consensus among the aforesaid specialists. Reliability was ensured during the pretest and was retested again in two weeks.

The questionnaire was pre-tested on 10 doctors randomly selected from the Facebook social media account of the principle investigator, employed at institutions under the Ministry of Health, regardless of their current work station or age. As per the results of the pilot study, one question was substituted (in the 'clinical management' domain) considering the 80% incorrect response rate, while some other questions were rephrased prior to the proper dissemination of the questionnaires via social media between 7th March to 15th August 2017.

Questionnaire was structured to collect the demographic details of the participant, knowledge under 4 separate domains; (basic principles, service organization, clinical management and ethical considerations) each domain containing 4 questions, followed by their opinions, where ten statements were listed for the participants to express their level of consonance on a scale.

Logging into personal accounts, reading the information followed by checking the "tick-box" was considered equivalent to informed consent. Duplicate submissions from same account were blocked.

Social media profiles of the graduates were retrieved from a representative/s from each faculty with which the form was shared individually and directly by the investigator. Non-responders were reminded twice more at monthly intervals from the initial contact. The messages included a request to circulate the form among fellow batch-mates thus employing 'snow balling sampling method (11) there-on.

Statistical Analysis

Data was analyzed using SPSS 20 software. The average percentage scores relevant to the level of knowledge of the doctors were assessed overall and under each domain. A score of 50% or more was regarded to be indicative of

adequate knowledge for medical graduates by the aforementioned specialists.

The existence of a significant correlation of the knowledge levels with sociodemographic factors was assessed using Pearson χ^2 (chi-square) adopting a significance level of 5% and a confidence level of 95%.

The level-of-agreement categories (agree, neutral or disagree) of the participants regarding each statement were assessed in percentages and contrasted with current (albeit conflicting) evidence.

Results

Of the total intake of 1215 graduates to all state medical faculties in the relevant academic year (12), 1186 had faced the final MBBS examination out of whom 981 have subscribed to social media groups of the relevant batch. Response rate was 35.8% (n=351). The demographic details of the respondents are illustrated in Table 1.

Table 1

Basic Knowledge on Palliative Medicine

The average score for the entire knowledge section was 37.23% (Standard deviation (SD) = 11.975%). The score distribution is illustrated in Table 2.

Table 2

Gender, age, medical school of graduation, employment status, religion and ethnicity did not have a significant effect on their scores. Analysis revealed a significant discrepancy only between the knowledge levels between service organization and clinical management domains ($p=0.019$) in individual respondents.

Opinions regarding palliative care

The results are illustrated in Table 3 in terms of the level of consonance with each statement.

Table 3

Critical Discussion

Since the study was representative of all the medical schools in Sri Lanka (with each school's response rate 18% or above), their knowledge and opinions reflect those of all young doctors.

Knowledge gap

The results demonstrate a deficiency in palliative care knowledge among the medical undergraduates of Sri Lankan Universities which may reflect suboptimal education. Of the four domains assessed, the graduates lacked knowledge in clinical, organizational and ethical imperatives; nevertheless, they were sufficiently aware about 'general principles' (scoring 62.6%) that delineate the scope of the discipline. Hence their opinions on how to implement palliative care in the Sri Lankan context were valued.

This calls for an urgent need to integrate palliative care efficiently into the undergraduate academic curricula to meet the ever-rising demand for it in the country with inter-disciplinary liaison between all clinical departments. Emphasis should be concentrated on areas with weaker knowledge; especially ethics which form the core of palliative care (13,14).

Opinions held

Majority (85%) of the young doctors felt a potential incline in the number of patients with palliative needs, which keeps on a par with the rising elderly population surviving terminal illnesses (2,15–17). Traditionally palliative care caters for life-limiting chronic illnesses. But there is emerging evidence that application of same principles of management into acute care (e.g. trauma) settings may be associated with improved patient outcomes (18,19). Forty eight percent believed that all patients must be entitled for palliative care regardless of acute or insidious progression into the terminal illness (20).

"Patients should be informed about their prognosis be it favourable or otherwise"

"Loved ones should decide which details about the illness the patient should receive"

Above two statements from the questionnaire relate to areas of controversy. Where truth-telling practice is predominant in the western world, 'hiding bitter truth' was particularly found to be justifiable in many eastern cultures (21,22). Hence it is suggested by recent literature to honor the patient's autonomy in receiving information catered to his wishes (23). However, colluding with the patient in terms of illness-related facts such as prognosis, is regarded to be detrimental overall with current evidence. It is found to lead to emotional distress, demoralization and also render them unable to formulate care plans for the future or attend to unfinished business before it is too late (24). In our study, 68% believed it was appropriate to reveal the prognostic information to the patients in spite of the content, while 31% believed that the next-of-kin should censor the information reaching the patient.

Forty percent of the doctors believed that steroids enhance the overall quality of life of patients, 47% remained neutral while the rest disagreed to this statement. Corticosteroids are being prescribed for many non-specific symptoms such as anorexia-cachexia symptoms, nausea, pain and breathlessness (25). Steroids are expected to improve appetite, resolve fatigue and oedematous collections in tissues, thus assisting to improve quality of life (26,27). Role of steroids in addressing specific causes such as neurological complications (e.g. spinal cord compression), soft tissue infiltrations (e.g. abdominal tumours) etc. have only yielded weak evidence so far (25). Simultaneously, steroids also contribute significantly to the adverse effect burden (25,28,29). Therefore, the net benefits over harms of steroids on palliative patients is an area pending further investigations.

The uniqueness of the discipline of palliative care lies in the holistic approach to care with more weightage on respecting clinical ethics (30,31). Theory on how palliative care should be practiced does not necessarily dictate or oblige healthcare providers to comply with aspects that preserve ethics. This is partially attributable to the potential psychological ailments resulted such as compassion fatigue, moral distress and burnout (32,33) among the health staff. However, the expected difference between the care approach of palliative physicians as opposed to others was seemingly apparent to 68% of the young doctors.

Globally, the facilities available for non-cancer patients to receive palliative care remain suboptimal at present (34). Albeit the spectrum of conflicting evidence from international studies (35–38), 76% of the respondents have

perceived that the symptom and healthcare burden of non-malignant diseases outweigh those of cancer.

Despite the general consensus that palliative care improves quality of life of patients at home, hospice and hospital levels, there are controversies with regards to which levels are most appropriate for the particular countries or settings depending on the financial resources, existing health infrastructure and human resources with necessary expertise etc. (39–43) The majority (>90%) believed that de-novo establishment of each or either of hospice, hospital based or home based palliative care services would sustainably improve overall patient care. These are important areas to be objectively explored with future studies that will provide base for appropriate health recourse allocation at the very inception of establishment of palliative care facilities in the country.

Limitations

The absence of a standardized, validated questionnaire to formally evaluate the level of palliative care knowledge among (undergraduate) medical doctors as of this time was the most significantly perceived limitation of the study. Graduates who have not subscribed or not active on social media groups were technically inaccessible to be evaluated. Compliance with the instructions, only for the MBBS pass finalists to take part in the survey was untraceable. However, the posts were exclusively limited to “closed member groups” of particular batches of graduates and this potentially prevented the questionnaire from reaching unauthorized parties.

There would have been participants who availed themselves on-line study material while participation. It was also noted that, out that out of the doctors among whom the survey was distributed, those who had a particular interest for the discipline of palliative care and/or those who were enthusiastic academics spent time to take part as opposed to the remainder.

Declarations

Ethics approval and consent to participate: Ethical approval No: 07/17 was obtained from the Ethics Review Committee, Faculty of Medical Sciences, University of Sri Jayewardenepura, Sri Lanka. Reading the information provided prior to entering the form, understanding the freedom to withdraw from the study at any stage and submitting it which had been sent to their personal social media accounts was considered as equivalent to informed consent.

Consent for publication: Not applicable

Availability of data and material: The datasets generated during the current study have been also available from the corresponding author upon reasonable request.

Competing interests: The authors; GVMC Fernando and S Prathapan declare that they have no competing interests.

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Authors' contributions: GVMCF conceptualized, designed the study, collected data, analysed and wrote the article. SP contributed in the capacity of a methodological expert to formulate the study design, write and approve the final version of the research article. GVMCF and SP both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the

author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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Tables

Table 1: Sociodemographic characteristics of the population assessed

| Gender | Number (Percentage) |
|----------------------------|---|
| Male | 146 (42%) |
| Female | 205 (58%) |
| Age | Value/s |
| Mean age (years) | 25.81 |
| Age range (years) | 23-28 |
| Standard deviation (years) | 0.87 |
| Religion | Proportion (Number and Percentage) |
| Buddhist | 275 (78.35%) |
| Hindu | 29 (8.26%) |
| Islam | 23 (6.55%) |
| Catholic | 14 (3.99%) |
| Christian | 6 (1.71%) |
| Atheist | 4 (1.14%) |
| Ethnicity | Proportion (Number and Percentage) |
| Sinhalese | 293 (83.48%) |
| Tamil | 33 (9.40%) |
| Moor | 23 (6.55%) |
| Bhutanese | 2 (0.56%) |
| Employment | Proportion (Number and Percentage) |
| Temporary demonstrator | 150 (42.74%) |
| Research assistant | 83 (23.65%) |
| Locum medical officer | 54 (15.38%) |
| Not employed | 58 (16.52%) |
| Other | 6 (1.70%) |

Table 2: Illustration of knowledge scores

| Domains | Percentage of "correct" responses and standard deviation (SD) | Percentage of "incorrect" responses | Percentage of "uncertain" responses | Percentage of respondents who scored > 50% |
|---------------------------|---|-------------------------------------|-------------------------------------|--|
| A. General Principles | 62.60% (SD=24.5%) | 25.57% | 11.82% | 82.9% |
| B. Service Organization | 34.54% (SD=17.6) | 29.27% | 36.18% | 40.7% |
| C. Clinical Management | 32.26% (SD=22.3) | 38.96% | 28.77% | 36.8% |
| D. Ethical Considerations | 19.53% (SD=20) | 56.54% | 23.93% | 20.8% |
| Overall | 37.23% (SD=11.975) | 37.59% | 25.18% | 17.7% |

Table 3: Detailed analysis of individual opinions of the doctors

| Statement | Agree | Neutral | Disagree |
|--|-----------|-----------|-----------|
| "The number of patients in need for palliative care is on the rise" | 298 (85%) | 37 (10%) | 16 (5%) |
| "All dying patients should receive palliative care" | 169 (48%) | 82 (23%) | 100 (29%) |
| "Patients should be informed about their prognosis be it favourable or otherwise" | 238 (68%) | 89 (25%) | 24 (7%) |
| "Family/Loved ones should decide which details about the illness the patient should receive" | 108 (31%) | 102 (29%) | 141 (40%) |
| "Steroids improve the quality of life of palliative patients" | 140 (40%) | 164 (47%) | 47 (13%) |
| "There would be no difference in the way a patient with a terminal diagnosis is approached by a Palliative Specialist as opposed to other specialists" | 49 (14%) | 65 (18%) | 237 (68%) |
| "More hospices should be established in Sri Lanka" | 312 (89%) | 34 (10%) | 5 (1%) |
| "Introduction of a "Hospital Palliative Care Team/Unit" will improve patient care in Sri Lankan hospitals" | 334 (95%) | 16 (5%) | 1 (0%) |
| "Home based palliative care is much required by Sri Lankan society" | 317 (90%) | 29 (8%) | 5 (2%) |
| "The burden of other non-communicable diseases is less frequent than that of cancer" | 56 (16%) | 29 (8%) | 266 (76%) |

Supplementary Files

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