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Editorial

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Palliative Nutritional Care for Cancer Patients

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INTRODUCTION

Palliative care is of paramount importance for patients suffering from life threatening incurable diseases such as AIDS, cancer, end stage renal disease and end stage chronic illnesses.¹ In the Indian healthcare system, palliative care is a developing area and is not well represented in the health sector. Medical advancements, cancer survivors are leading a longer and better quality of life but still there is a gap between availability of palliative care centers and assistance from healthcare professionals.²

PREVALENCE OF CANCER

International Agency for Research on Cancer (GLOBOCAN project, 2012) reported approximately 14.1 million new cancer cases and 8.2 million cancer deaths worldwide. Out of these there were 1015,000 cancer cases and 683,000 cancer deaths in India.³ It has been predicted that the number of cancer deaths in India will rise from 683,000 in 2012 to 1.2 million by 2035.³ The World Health Organization (WHO) estimates 1 million new cancer patients yearly in India with approximately 750,000 of them requiring palliative care.¹

CANCER CACHEXIA AND ITS IMPACT ON NUTRITION

In cancer, with disease progression, a patients' nutritional status is progressively impacted. The multiple metabolic changes and nutritional depletion may affect body composition, functional capability, psychological state and response to cancer treatment.⁴ Gastrointestinal and head and neck cancers are widely associated with cachexia. However the same tumor site may exhibit cachexia of varying grade or be absent in different patients. Approximately 50% of cancer patients progress to cachexia.⁵

Cancer cachexia was defined as "a multifactorial syndrome defined by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment. Its pathophysiology is characterized by a negative protein and energy balance driven by a variable combination of reduced food intake and abnormal metabolism".⁶ There are three stages of cancer cachexia: pre-cachexia, cachexia and refractory cachexia. In the precachexia stage patients experience less than 5% pre-treatment weight loss whilst once they progress to refractory cachexia stage mortality is foreseen in approximately three months.⁶

During cancer, patients nutritional status is hindered due to tumor induced alterations in metabolism.⁷ Patients also suffer from tumor related problems and chemo-radiotherapy induced dysphagia, mucositis, xerostomia, nausea, vomiting, sometimes chewing and swallowing difficulties.⁸ The capacity to endure chemo-radiotherapy treatment and fight the disease is adversely affected by cachexia.⁹ Alongside the minimum 10% increased in basal metabolic rate,¹⁰ anorexia is one of the key factors among cachexia patients leading to weight loss.¹¹ Body

weight loss during cachexia is due to skeletal muscle as well as adipose tissue wasting.¹² The wasting of skeletal muscle leads to deranged immune system and mobility issues.¹³ As weight loss progress to 30% of pre treatment body weight, death becomes inevitable.¹⁴

CONSEQUENCES OF MALNUTRITION

Malnutrition is described as a clinical condition of imbalance of energy, protein, and other nutrients. This leads to significant negative impact on body composition, function, and clinical treatment.^{15,16} Malnutrition has been documented globally among 30-80% of cancer patients.¹⁷⁻¹⁹ The consequences of malnutrition may include an increased risk of morbidity, decreased response and tolerance to treatment, a decline in quality of life, higher health-care costs and reduced survival.²⁰⁻²² Reported dietary intake of advanced cancer patients suggests that their total calorie intake is 1610±686 kcal/d which is 4-53 kcal/kg body weight/d.²³ Kumar et al also documented a calorie deficit of approximately 250-400 kcal/d among weight losing cancer patients.¹⁸ Anemia is commonly reported in advanced cancer patients, leading to altered energy homeostasis and reduction in physical activity.²⁴ Advanced cancer patients have deficiency of essential micronutrients like zinc, selenium, vitamin C and vitamin E, which support body's immune response.²⁵⁻²⁸

NUTRITION SCREENING AND ASSESSMENT OF CANCER PATIENTS

Nutritional screening and body weight measurements assists in nutritional status evaluation of cancer patient's non-invasively.²⁹ It helps to identify malnourished patients or those who are at risk of developing malnutrition. Patients' nutritional status can be monitored and a nutritional care plan can be developed. Body composition machine can be used to assess the body weight, body fat percentage and muscle mass of ambulatory patients.³⁰ A range of subjective and objective measures have been used for nutritional screening like 24-hour dietary recall, food frequency questionnaire (FFQ), Patient Generated-Subjective Global Assessment (PG-SGA). FFQ and 24 hour dietary recall help to record patients' frequency of individual foods consumption and information on eating patterns.³¹ PG-SGA questionnaire aids to determine the deterioration or improvement in their nutritional status.³² It has been recommended as the nutrition assessment tool for patients with cancer by Oncology Nutrition Dietetic practice group of the American Dietetic Association.³²

QUALITY OF LIFE ASSESSMENT FOR CANCER PATIENTS

Cancer and treatment-induced changes in metabolism can lead to alterations in physiological and psychological functions. This may lead to low quality of life and consequently adversely influence patients' nutritional status.³³ Various tools for quality of life assessment have been developed; European Organization for Research and Treatment of Cancer quality-of-life core questionnaires (EORTC QLQ-C30), the Functional Assessment of Cancer Therapy-General (FACT-G), Functional Living Index cancer questionnaire (FLIC), Spitzer Quality of Life Index (QLI), Rotterdam Symptom Check List (RSCL), the Medical Outcome Study 36-item short form (MOS SF-36), EuroQol (EQ-5D), the Cancer Rehabilitation Evaluation System (CARES) and the Symptom Distress Scale.³⁴ The European Organization for Research and Treatment of Cancer-Quality of Life (EORTC QLQC30) questionnaire is a validated self assessment instrument used for assessing quality of life in patients with cancer and most widely used tool.^{34,35} Studies involving malnourished cancer patients suggest a strong association between body weight loss and fatigue with poor quality of life, functional impairment and early mortality.^{36,37}

EXERCISE FOR THE MANAGEMENT OF CANCER RELATED FATIGUE

Development of cachexia may lead to decline in daily motor activities and increased fatigue. Endurance activity has been noted to decrease self reported cancer related fatigue.³⁸ Clinical Practice Guidelines on Cancer Cachexia in Advanced Cancer Patients by European Palliative Care Research Collaborative 2010 strongly recommends physical activity in the management of cancer related cachexia.³⁹ It may help to enhance the immune function and reduce inflammatory responses.⁴⁰ Physical activity questionnaire like Global Physical Activity Questionnaire (GPAQ) and Karnofsky Performance Score (KPS) are reliable tools to assess patients physical functioning.^{41,42} A study on 188 advanced palliative cancer patients who were enrolled under a 12-week physical activity program (mainly walking) observed strong improvement in fatigue levels and maintenance of body weight.⁴³ Another study, observing daily physical activity of advanced cancer patients showed significant correlation between activity levels and different domains of quality of life.⁴⁴

NUTRITION INTERVENTION AND ITS BENEFITS

Oral Nutritional Supplements (ONS) containing protein, fat, carbohydrates, vitamins and minerals can provide a convenient and practical way of providing adequate nutritional support to distinct patient categories. Consumption of energy intake of

28.7-34 kcal/kg ideal body weight/day and protein intake of 1.4 g/kg ideal body weight/day in cancer cachexia patients can help in weight maintenance.^{45,46} Patients experiencing weight-loss due to cancer cachexia can have better quality of life if their weight is stabilized compared to weight losing patients.⁴⁷

For management of cachexia patients, a multimodal therapy approach has been proposed.³⁹ A multimodal therapy involves nutritional support, anti-inflammatory and anemia therapy, encouraging physical activity, oral nutritional supplement intake and multidisciplinary teamwork approach in order to improve nutritional status of the patient.⁴⁸ According to a recent systematic review, malnourished cancer patients, receiving nutritional counseling along with or without ONS resulted in nutritional status improvements.⁴⁹ Body weight increase in cancer patients consuming ONS leads to maintenance of lean body mass and better quality of life.⁵⁰ Better nutritional status among head and neck as well as gastrointestinal tract cancer patients consuming ONS compared to patients receiving standard care has been reported earlier.⁵¹ A recent nutritional intervention study among low socio-economic malnourished head & neck patients, reported increased percentage body weight and improved biochemical indices compared to control patients on daily diets.⁸ The patients were given a diet chart consisting of locally available and acceptable low cost nutritional food items, which could be easily adhered with.⁸ Another ongoing intervention study is testing the acceptability and impact of a natural nutritional flour mix (IAtta) on improving nutritional status of cachexic female cancer patients.⁵² Educating caregivers about employing affordable nutritious local foods among malnourished cancer patients could help in correcting their nutritional status with minimal training. This is irrespective of their financial status as well as their area of residence.⁵² Baldwin et al, in the past concluded that nutritional intervention among advanced malnourished patients was significantly correlated with better quality of life.⁵³ Furthermore, nutritional supplements containing protein, fat, carbohydrates, vitamins and minerals can provide a convenient and practical way of compensating their inadequate daily diets. Dieticians should be actively involved in providing patients' individualized nutritional counseling keeping their preferences, ethnicity and cultural restrictions in mind.⁵⁴ During nutritional counseling sessions, attention should be paid to the kind of treatment patient is undergoing as chemo-radiotherapy side effects impact food intake. Enteral, parenteral, total parenteral nutrition feeding techniques should be considered in patients who are unable to take oral foods.⁵⁴ Oncologists and clinical nutrition experts need to work in collaboration to optimally manage malnutrition among cancer patients.

CONCLUSION

Therefore, palliative cancer patients' nutritional status should be regularly monitored and supplementation should be recommended to compensate deficit calorie intake. We can then manage body weight loss and predict improved treatment outcome leading to a better quality of life. Patients in palliative care should be counseled for nutritional intake according to their individual needs and food preferences.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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Mini Review

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Glioblastoma, the Neurosurgeon, and Neuro-Palliative Care

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ABSTRACT

Primary malignant brain tumors, such as Glioblastoma multiforme (GBM), carry a poor survival prognosis and lead to a high burden of symptoms for the patient and his/her family. While advances in treatment modalities have led to increased survival rates for patients with GBM it remains a terminal diagnosis. Recent data has demonstrated that patients who receive early palliative care in addition to standard oncological therapies for non-neural cancers have a better quality of life, receive fewer aggressive treatments, and live significantly longer than those who do not receive early palliative care. To date, palliative care has arguably been an underutilized approach to assist in the management of GBM patients. Patients living with brain tumors have symptoms that differ from patients suffering with non-neural cancers, which raises the future possibility of physicians that are dedicated to palliative management of patients with neurological conditions, such as GBM. Common symptoms for patients actively dying with GBM include headaches, seizures, somnolence and fatigue, dysphagia, focal neurological deficits, and cognitive deficits. Neurosurgeons often have early contact with newly diagnosed brain tumor patients. Therefore, it is of utmost importance for the neurosurgeon to have an appreciation of palliative care for this specific patient population and to also have an understanding of the full spectrum of care that these patients will encounter while living, and dying due to GBM. The purpose of this paper is to review the existing literature surrounding palliative care for patients with malignant brain tumors particularly from the perspective of the neurosurgeon and because of the unique symptoms faced by this patient population introduce the concept of neuro-palliative care.

KEYWORDS: Neurosurgery; Glioblastoma; Brain tumor; Palliative care; Neuro-palliative care.

ABBREVIATIONS: GBM: Glioblastoma multiforme; ICU: Intensive Care Unit.

INTRODUCTION

The neurosurgeon is well versed in end of life scenarios.^{1,2} Traumatic head injuries, massive intracranial hemorrhages, and brain tumors are common situations that neurosurgical teams are tasked to deal with, and often, palliative management is appropriate. A unique end of life situation for the neurosurgeon, that spans the full spectrum of care from the operating room to palliative care, is the treatment of highly malignant brain tumors such as glioblastoma multiforme (GBM).

Glioblastoma multiforme (GBM), the most common adult primary brain cancer carries a median survival of less than 18 months with available therapies.^{3,4} Much of the effort to understanding treatment of GBM has been from the perspective of molecular biology.⁵⁻⁷ Despite laboratory discoveries and the progression of survival due to advances in surgery, radiotherapy, and chemotherapy,^{3,8-10} GBM remains a devastating disease that essentially ensures a very poor long-term survival.¹¹ However, several studies have identified patients who have lived longer than 10 years after their initial diagnosis of GBM.^{3,12,13} The rare numbers of patients on the tail

of the survival curves may contribute to a sense of therapeutic optimism that is maintained by physicians and hoped for by patients, which may contribute to a lack of early involvement of palliative care physicians. Despite patients receiving the terminal diagnosis of GBM, palliative care has not been thoroughly utilized as a means of care for patients suffering with GBM or other malignant brain tumors.¹⁴

The term 'palliative care' was initially coined by Canadian oncologic surgeon Balfour Mount¹⁵ who set up the first North American palliative care unit in the 1970's after being inspired by early work done in Britain. The use of the term 'palliative care' was an intentional decision in order to distinguish the field from that of hospice care, which was typically associated with hospices run by religious groups dedicated to end of life care when no further treatments remained.¹⁶ Palliative care is a relatively young field of medicine that has now expanded its scope to manage chronic conditions such as chronic obstructive lung disease or progressive neurological conditions such as motor neuron disease and dementia. However, the genesis of palliative care is strongly rooted in the care of oncology patients. Despite its recent introduction, palliative care has progressed quickly from end of life care to become an actual treatment option itself. A landmark study by Temel, et al.¹⁷ demonstrated that lung cancer patients randomized to early palliative care in addition to standard therapy had a better quality of life, received fewer aggressive treatments, and lived significantly longer than patients undergoing standard therapy alone. The study by Temel and colleagues demonstrates that benefits of comprehensive medical care (standard therapies with simultaneous palliative care) for patients diagnosed with non-small cell lung cancers. Malignant non-small cell lung cancer is known to afflict patients with a high burden of symptoms, leading to a poor quality of life, and a prognosis of less than one year survival.¹⁷

GBM is also a malignant disease associated with a high burden of symptoms and a very poor survival prognosis. Despite the abysmal prognoses for these patients, palliative care has not been explored as an adjuvant treatment to the standard therapeutic regime for GBM. Treatment of GBM is dependent upon a multidisciplinary approach that includes neurologists, oncologists, radiation-oncologists, and neurosurgeons.¹⁸ Typically, palliative care is left out of this multidisciplinary approach until near the end when all treatment options are exhausted.¹⁴ However, given the recent high quality data from Temel, et al. demonstrating that early palliative care can provide multiple benefits to cancer patients, including significantly longer survival, it is a possibility that early palliative care may also be implemented to care for GBM patients.¹⁹ Although the implementation of early palliative care for brain cancer patients is possible there is little existing data on how best to navigate that route.

The primary purpose of this paper is to review and discuss the existing palliative care literature specifically relating to primary brain tumor patients and particularly from the perspective of the neurosurgeon. A second aim of this paper is

to introduce the concept of neuro-palliative care. Patients living with brain tumors have symptoms that differ from patients suffering with non-neural cancers, which raises the future possibility of physicians that are dedicated to palliative management of patients with neurological conditions, such as GBM. Neurosurgeons often have early contact with newly diagnosed brain tumor patients. Therefore, it is of utmost importance for the neurosurgeon to have an appreciation of palliative care for this specific patient population and to also have an understanding of the full spectrum of care that these patients will encounter while living, and dying due to GBM.

End of Life Symptoms of Patients with Brain Tumors

Examination of symptoms at end of life for GBM patients is the most studied aspect of end of life care in this patient population²⁰ and there is a broad range of symptoms experienced.²¹ Common symptoms for patients actively dying with GBM include headaches, seizures, somnolence and fatigue, dysphagia, focal neurological deficits, and cognitive deficits.²¹⁻²⁵ While pain and fatigue are associated with many types of malignancies, other symptoms such as seizures, cognitive dysfunction, and focal neurological deficits are more common in the neuro-oncology population. The studies evaluating end of life symptoms in GBM patients are limited by their small sample sizes and retrospective designs that hinder treatment recommendations for management of these symptoms. Common methods for treatment of end of life symptoms include anti-epileptic medications for seizures, steroids to manage raised intracranial pressure causing headaches, and opioids for pain management.^{21,26,27} Even with limited data to direct treatments for GBM patients at the end of life there are aspects of care that are successfully managed.

A recent survey of caregivers of GBM patients indicated that there are high levels of satisfaction with treatment of dysphagia and epilepsy but cognitive deficits were deemed to be treated less effectively.²² On one hand these findings may be attributed to side effects of medications such as steroid induced agitation or anti-epileptics leading to cognitive dysfunction.^{20,28} On the other hand, an intrinsic disease of the brain, such as GBM, is likely to impart cognitive dysfunction on patients that manifests as lethargy, seizures, confusion, and delirium regardless of treatment side effects.²³ Occasionally, palliative sedation is employed in the end of life period to combat the distressing cognitive changes associated with GBM.^{20,21,28} Unfortunately the use of palliative sedation is complicated due to the fact that treating physicians may not know the patients' expressed wishes and that many patients, during the end of life, are unable to participate in making decisions about their care.²⁶

Perspectives of GBM Patients During End of Life

Of course the most important aspect in the management of GBM, from diagnosis to palliation, is the patient. Several studies have examined patient opinions related to quality of

life while receiving palliative care for GBM. Quality of life encompasses functional status, emotional well-being, and may be thought of as a marker of contentment that is different for each patient.²⁰ Clinical trials typically assess imaging progression, performance status (Karnofsky Performance Status), or handicap (modified Rankin Scale). Assessing a patient's well-being in a standardized manner is a challenging endeavor and therefore the existing studies in GBM patients have been qualitative in nature. Mummudi and Jalai,²⁰ highlight that a GBM patient's quality of life depends on multiple variables such as their performance status, tumor grade²⁹ (high-grade gliomas lead to worse quality of life), tumor location³⁰ (frontal or temporal-parietal lesions may be associated with mood disturbances), and treatment factors such as radiation dose.³¹⁻³³

Given the myriad of factors that influence quality of life when patients are dying with GBM, Pace, et al.²³ attempted to focus strictly on the management of end of life symptoms (headache, dysphagia, etc.). Pace, et al. demonstrated that patients were often unable to participate fully in end of life decisions as about 50% of patients in their cohort were not fully aware of their prognosis, however capacity was not formally assessed in this study. To complicate matters, it was also revealed that only 6% of these GBM patients had advanced care directives. Together, the decreased awareness surrounding prognosis and the lack of advanced care directives contributes to exceedingly challenging clinical scenarios which are compounded by family members being left to make decisions due to the fact that most GBM patients exhibited a progressive loss of consciousness in the last weeks of life.²³

Quality of life is a concept that, for GBM patients, may be the most important aspect of their care. To investigate the attitudes of death and dying in patients diagnosed with terminal brain cancer, Lipsman and colleagues³⁴ interviewed a sample of patients who were cognitively intact, suggesting that each patient was not in the very final end stages of life. This study highlights the premium that patients put on quality of life, rather than prolongation. To demonstrate this, patients in their study overwhelmingly would choose a surgery that would prolong life by three months with fewer deficits than an operation that would extend life by a year but leave the patient highly disabled. Additionally, patients who are faced with terminal brain cancer place a very high value on mental function and cognition and the possibility of losing those faculties would be a reason to decline further treatment.

Care Giver Opinions of Palliative Care

Neurosurgeons commonly assist in managing end of life scenarios for patients, particularly in the Intensive Care Unit (ICU). A survey of caregivers who had a family member pass away in the ICU rated the quality of death as very favorable when cared for by a neurosurgeon, as compared to other specialties.¹ These differences likely reflect the fact that neurosurgeons are often faced with end of life scenarios and are reasonably well

versed at navigating those difficult scenarios. Despite the high satisfaction levels that patients' families have of neurosurgical teams during end of life care in the ICU it remains very rare that neurosurgeons are involved with end of life care for GBM patients. Several studies have attempted to gauge the satisfaction of caregivers (typically family members) with the palliative care received by relatives living with GBM. Using surveys to assess caregiver satisfaction, several studies have demonstrated high rates of caregiver satisfaction during end of life care (54-90% were satisfied).^{22,26,28} Although palliative care for GBM patients is associated with satisfaction it is still an immense challenge to effectively manage symptoms in this patient population. Dedicated neuro-oncology teams could be a potential strategy to deal with the myriad of challenging symptoms experienced by brain cancer patients. A European survey revealed that less than ten percent of such patients were supported by neuro-oncology teams during the end of life,²² which may underscore or exacerbate challenges faced by physicians delivering treatment in this patient population.

Decision Making of Physicians Providing End of Life Care to GBM Patients

Utilizing a retrospective questionnaire Sizoo, et al.²⁶ surveyed physicians in The Netherlands who cared for glioma patients in the last three months of their lives, with particular attention paid to the last week of life. The aim of the survey was to assess the end of life preferences of patients and also the medical decisions carried out by physicians during this time. This study highlights that only 60% of physicians caring for GBM patients at the end of life knew of explicit end of life decisions that the patient would have wanted. For the majority of physicians responding to the survey they did not know their patient's wishes relating to life prolonging treatment, admission to hospital, palliative sedation, or euthanasia. Surveyed physicians reported that about 50% of patients were deemed not capable of making end of life decisions in their last weeks of life due to progression of their cancer leading to cognitive disturbances, somnolence, aphasia, and delirium. Interestingly, 10 patients from this study requested euthanasia and seven were granted this request. This study demonstrates the immense challenges to be faced in managing end of life scenarios for GBM patients. Furthermore, this study highlights the need for early discussions surrounding advanced care directives for patients diagnosed with GBM, a role that the neurosurgeon as an early point of contact may be well positioned to initiate.

Cost Effectiveness of Palliative Care for GBM Patients

A substantial portion of health care expenditure occurs towards the end of patients' lives.^{35,36} Although the cost of treatment for an individual patient should not necessarily be forefront in a physician's mind, it is nonetheless prudent to consider cost-effectiveness for treatments, especially when palliative in nature. Pace, et al.²⁵ examined 72 GBM patients enrolled in a palliative home-care program (after no further treatments were

offered) and compared the cost-effectiveness of this approach to 71 patients not enrolled in the program. Patients enrolled in the palliative home-care program were less likely to be admitted to hospital and when admitted spent significantly fewer days in hospital. Together, these differences led to significantly lower hospitalization costs for patients with palliative care during their last months of life (517 Euros vs. 24,076 Euros).²⁵

Survival of GBM Patients with Palliative Care

In studies of cancer therapies survival is the gold standard for outcome measures. The study of early palliative care for lung cancer patients by Temel, et al.¹⁷ was deemed a landmark trial not because the treatment group had a reduction in their symptoms but because they were deemed to have statistically and clinically longer survival. Pace, et al.²⁵ examined a small sample of GBM patients, in the end stages of their lives, who were enrolled in a palliative home-care program and compared their survival to a cohort of GBM patients who were not enrolled in the program. It should be mentioned that none of these patients were enrolled in early palliative care starting at the time of GBM diagnosis. There were no statistical differences in median survival times between the two groups but a trend favoring palliative care was shown (Palliative care: 13.2±16 vs. comparison cohort: 11.2±7.7 months).

DISCUSSION

Advances in laboratory science have been translated into increased survival for patients diagnosed with GBM.⁵⁻⁷ Despite these advances the prognosis for patients living with GBM is very poor and remains essentially a palliative diagnosis, but little is known about the palliative phase in this patient population. Here we have discussed the existing literature surrounding palliative care of patients with GBM. Symptoms experienced by this patient population have been studied, in a retrospective manner, by several groups.²¹⁻²⁵ Other aspects that have been examined during the palliative phase of life for GBM patients include patient perspectives at end of life, caregiver opinions, physician decision making, cost-effectiveness, and survival duration.

Although limited by a small number of studies, several interesting points that directly impact patient care have arisen by reviewing the palliative care literature of GBM patients. The first is that symptoms experienced by patients as they are passing away with GBM have been well documented.²¹⁻²⁵ Understanding the full spectrum of GBM as a disease allows the neurosurgeon to fully inform their patients of the treatment options and progression of GBM to maximize quality of life. The second important piece garnered from the literature surrounds decision making at end of life. Pace, et al.²³ reported that only 6% of patients in their cohort study had advanced goals of care. Goals of care can change for patients as their disease progresses but the neurosurgeon, as an early point of contact for those diagnosed with GBM, can be vital in starting this discussion. Early and

regular discussion regarding goals of care is associated with a higher quality of life for the patient as well as increased survival rates.¹⁷ An additional benefit of early discussions regarding care during the end of life for GBM patients is less stress for family members.²⁸ Additionally, quality of life is increasingly being suggested as an end point in clinical studies.²⁰

The majority of patients with a terminal cancer diagnosis will experience symptoms that are distressing to them such as pain, nausea, and vomiting. The literature suggests that patients with GBM face symptoms that patients with other cancers will routinely not. Due to direct involvement of the brain by GBM and other malignant brain tumors patients will suffer symptoms such as seizures, headaches, and somnolence leading to alterations in their cognitive status,^{23,24} as compared to patients with malignant abdominal or thoracic cancers who would not be, unless they have brain metastases. Perhaps due to the terminal nature of a GBM diagnosis patients will choose quality of life, especially intact cognitive performance, over a life prolonging treatment that would be associated with disability.³⁴

Due to the unique symptoms faced by patients living and eventually dying with serious neurological diseases the needs of these patients often differ from other palliative patients. Management of these complex situations should ideally be performed by practitioners with expertise in symptom management of terminal neurological conditions, leading to the formation of neuro-palliative care as a subspecialty of palliative care. Physicians dedicated to neuro-palliative care would aid in the management of patients with terminal neurological conditions in several ways. First, physicians who focus their practice on neuro-palliative care will ultimately provide better care to those who need it from the perspective of symptom management as well as discussions of goals of care. Second, a neuro-palliative care approach could also be employed with patient populations in resource limited settings or pediatric patients. Third, physicians with an interest and practice in neuro-palliative care would be able to conduct research in the area to improve symptom management strategies for patients with GBM and other neurological conditions throughout their disease. Given the recent high quality data from Temel, et al.¹⁷ demonstrating that early palliative care, in conjunction with standard oncologic care, for patients with metastatic lung cancer led to significant improvements in quality of life and longer survival it suggest that a similar trial would be worthwhile in GBM patients. Current literature in palliative care of patients with GBM indicates that patients are highly satisfied with a neuro-palliative approach,^{22,26,28} that it provides potential cost saving benefits, and that there may be a potential for increased survival,²⁵ although no study has examined early palliative care in conjunction with standard therapies for GBM patients. The current studies in palliative care for GBM patients are also limited by small samples and retrospective study designs. Together, these results suggest that a trial comparing early neuro-palliative care in conjunction with standard oncologic therapies to standard therapies alone for GBM treat-

ment would be well warranted.

In conclusion, studies of palliative care for patients diagnosed with GBM are limited in numbers and are usually retrospective in nature but have clearly described a constellation of symptoms that are unique to patients with malignant brain tumors at the end of life. These symptoms, often impacting cognitive domains lead to challenging delivery of care for the patient and family as well as the physician. The unique and difficult symptoms faced by patients with malignant brain tumors underscore the need for three simple recommendations to be considered for the care of this patient population.

1. Palliative care should be involved early on in the journey of a patient diagnosed with GBM.
2. Neuro-oncology teams should be involved throughout the duration of a patient's illness with GBM, including the final stages.
3. Palliative care physicians with expertise and interest in nervous system diseases should optimally be involved in the care of such patients (e.g. multiple sclerosis and motor neuron disease) and specifically for patients with malignant brain tumors their palliative physicians should be embedded with neuro-oncology teams during treatment.

CONFLICTS OF INTEREST

The authors have no conflicts of interest with respect to this work.

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Quality of Care for Older Patients with Non-Cancer Diagnoses under the End-of-Life Care Program

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ABSTRACT

Background: End-of-life (EOL) care is an important part of geriatric medicine in view of rapidly ageing populations in the world.

Aim: We aimed to evaluate the quality of care for older patients with non-cancer terminal illnesses, who died in 2010, under the EOL care program of an academic medical unit in Hong Kong. This unit consisted of an acute hospital, Prince of Wales Hospital (PWH) and a convalescence hospital (Shatin Hospital, SH).

Methods: This was a retrospective hospital-based audit of clinical effectiveness of the EOL service. We reviewed the quality of patient care during the final seven days of life. The quality of care was evaluated based on the compliance rates of five selected goals and the adoption of futile life-sustaining procedures and treatments.

Results: Case records of 129 patients in the EOL care program were analyzed. Two goals, including minimization of regular monitoring of vital signs and no blood taking, achieved over 70% compliance at SH and 0% at PWH. The compliance rates of discontinuation of non-essential medications were 46.4% in SH and 47.1% in PWH; and the compliance rates of switching essential medications to non-oral routes were 63.4% in SH and 70.6% in PWH (not statistically significant). The compliance rates of using as-required intravenous or subcutaneous medications were extremely low (<2%) at both hospitals. All futile life-sustaining procedures and treatments were initiated at the PWH.

Conclusions: We demonstrated significant differences in the quality of EOL care between the acute hospital and convalescence hospital. Greater emphasis on specialist training and education with allocation of resources may improve the EOL care in both settings.

KEYWORDS: End of life; Elderly; Chronic diseases; Advanced care plan; Palliative care.

ABBREVIATIONS: EOL: End-of-life; PWH: Prince of Wales Hospital; SH: Shatin Hospital; ACP: Advanced Care Plan; CHF: Congestive Heart Failure; COPD: Chronic Obstructive Pulmonary Disease; ESRF: End-stage renal failure; DNR: Do Not Resuscitation; AED: Accident and Emergency Department; LCP: Liverpool Care Pathway; WHO: World Health Organization; CPR: Cardiopulmonary resuscitation; AMT: Abbreviated Mental Test; OGD: Oesophago-gastro-duodenoscopy; LCP: Liverpool Care Pathway; ACP: Advanced Care Planning.

INTRODUCTION

End of life (EOL) care is increasingly recognized as an essential component of healthcare system, but the access to EOL care service is far from satisfying the demand, particularly with an aging population in the world.¹ It was also shown that older in-patients were more likely to suffer from inappropriate pain control and excessive interventions at the terminal stage of their lives.² Therefore, it is important to deliver high quality EOL care for frail older patients by setting up an Advanced Care Plan (ACP), offering adequate pain and symptom control without intention to hasten or postpone death, relieving caregivers' burden and strengthening rapport with the relatives.³⁻⁶ In Hong Kong, people usually died in the hospital instead of at home or in the residential home in view of social culture and legislations. Most of the EOL care was therefore conveyed through the hospital setting. However, previous studies of EOL care have reported dissatisfaction from patients and their family members about symptom control and failure to address their physical and psychosocial needs in the hospital setting.⁷⁻¹⁰ The aim of the study reported in this paper is to evaluate and compare the quality of EOL care for older patients with non-cancer diagnoses, in the acute and convalescence hospitals, by reviewing their clinical records during the last seven days of life.

EOL Care in Shatin Hospital, Hong Kong

With a capacity of 300 medical beds, shatin hospital (SH) offers a sub-acute, convalescence and step-down care for patients transferred from the prince of wales hospital (PWH), which provides acute general medical services in New Territories East region with 0.7 million populations of which 12% are people aged over 65. In order to improve the quality of EOL care for non-cancer older patients with chronic illness, SH medical unit launched an EOL care program in 2008 for those with non-cancer chronic illnesses including Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), End-stage renal failure (ESRF), stroke, dementia, other neurodegenerative diseases, and frailty who approach their end stage of life. The focus of this program was to palliate symptoms, enhance patient and family satisfaction with palliative care services, and allow the patient to rest in his home environment for as long as possible during the final phase of life. There were three commencing criteria:

1. Patient and relative not opting for active treatment; and
2. Existing Do Not Resuscitation (DNR) order; and
3. Satisfying the prognostic indicators of advanced disease of chronic illnesses.

After identifying a potential case for the EOL care program, the medical team in SH explain the program details to the patient and the family, and invite the patient to join the program by establishing an ACP and the DNR order. If the patient developed clinical deterioration, geriatricians might arrange direct

clinical admission to SH for him to receive EOL care in their terminal stage of life. The patient would still be managed by the general medical team as there was no special palliative team in SH for caring the EOL cases. However, if the patient was critically ill, given that SH did not have Accident and Emergency Department (AED), the patient was inevitably sent to AED in other hospitals, most likely to PWH, for immediate treatment, because ambulance paramedics have to transport emergency patients to the nearest AED according to the government guideline. The patient might subsequently be resuscitated in AED and admitted to acute medical units in PWH for further care.

Another similar project was undertaken in the oncology unit of another regional hospital in Hong Kong from July to September 2009 on the use of integrated care pathway for EOL patients with cancer. The compliance rates of the following six selected items ranged from 80-100%, including: 1) discontinuation of non-essential medications; 2) switching of essential medications to non-oral routes; 3) prescription of as-required intravenous or subcutaneous palliative medications; 4) minimization of regular monitoring of vital signs; 5) practice of flexible visiting hours; and 6) order of 'no further investigation'.⁹

In Hong Kong, there was a lack of data on the compliance of EOL care pathway in acute vs. convalescence medical units. A typical example would be the use of unnecessary life-sustaining procedures or treatments for older patients with terminal non-cancer diseases despite their wishes for comfort care.¹⁰⁻¹²

METHODS

Method

This was a retrospective hospital-based audit of clinical effectiveness of the EOL service in SH and PWH. We collected routine clinical data from the case notes and clinical management system to review and compare the quality of EOL care provided during the final seven days of life for patients in SH and PWH. Since this was a retrospective audit with no novel intervention or collection of identifiable data, our study has the necessary ethical approval

Patient Recruitment

We retrospectively reviewed the clinical records of all the patients of EOL care program who died in 2010. Their socio-demographic characteristics, residential status, diagnoses, comorbidities, clinical characteristics (functional status, cognition, long-term use of naso-gastric feeding, urinary catheter and oxygen therapy), which reflected their background functional status, were recorded and summarized.

Evaluation Criteria of the Quality of EOL Care

The quality of EOL care was assessed, based on: 1) the

compliance rates of five selected goals (see below), and 2) use of futile life-sustaining procedures and treatment in the last seven days of life. The five selected goals included: 1) discontinuation of non-essential medications, 2) minimization of regular monitoring of vital signs, 3) no blood-taking, 4) use of as-required intravenous or subcutaneous palliative medications, and 5) switching of essential medications to non-oral routes. These goals were adapted from the Liverpool Care Pathway (LCP) and the EOL care pathway used in the palliative care unit in Hong Kong, China. The compliance rate of each goal was calculated as the percentage of patients with goals achieved, with the gold standard being 100% compliance.

Regarding the first goal, the World Health Organization (WHO) recommended a list of essential medications for use in palliative care in 2013, including morphine, ibuprofen, amitriptyline, fluoxetine, diazepam, loperamide, lorazepam, haloperidol, metoclopramide, dexamethasone, hyoscine hydrobromide, docusate sodium, senna and lactulose.¹³ In this study, medications in the same group of those listed above were classified as essential medications for symptom control in the dying phase. On the contrary, continuation of anti-hypertensive drugs, anti-platelet drugs, glucose-lowering drugs, and mineral and electrolyte supplements in the last day of life was likely categorized as non-essential, but it should be reviewed case by case.

For the fifth goal, prescription of essential medications was reviewed on the last day instead of the final seven days because patients might be able to eat initially and oral administration of essential medications could be clinically appropriate then. Administration of medications *via* nasogastric or gastrostomy tube was considered appropriate in tube-fed patients.

Use of Futile Life-Sustaining Procedures and Treatments

Use of futile life-sustaining procedures and treatments during the last seven days of life included 1) Cardiopulmonary resuscitation (CPR); 2) non-invasive and mechanical ventilation; 3) use of inotropic agents and fluid resuscitation for hypotension or shock, and 4) the use of invasive diagnostic procedures. In Hong Kong, intravenous or subcutaneous hydration is commonly continued until death due to cultural reasons and family wishes, so this has not been counted as life-sustaining treatment in this audit.

Statistical Analysis

Categorical variables were presented as counts and percentages, and continuous variables as mean values with standard deviations. The compliance rates of five selected goals in SH and PWH were compared and tested if there was a statistically significant difference between two hospitals by using two samples z-test.

RESULTS

Clinical characteristics of EOL patients

Table 1 summarizes the clinical characteristics of 146 patients included in this audit. Over half (54.8%) of them were residing in nursing homes, and the mean duration of institutionalization was 4.2 years. Stroke, which caused significant disability and need for naso-gastric tube feeding, was the most common indication for EOL care (26%), followed by dementia (17.1%), chronic renal failure (15.8%), COPD (11.6%), congestive heart

Demographics	n (%) unless otherwise stated
Mean (SD) Age, years	83.4(±9.4)
Gender, male	66(45.2%)
Nursing home residents	80(54.8%)
Community-dwelling	66(45.2%)
Lived with children	30(45.5%)
Lived with spouses	29(43.9%)
Lived with other relatives	3(2.1%)
Lived alone	4(6.1%)
Availability of domestic helper	20(30.3%)
Main Diagnosis for EOL Care	
Stroke	38(26.0%)
Advanced dementia	25(17.1%)
Chronic renal failure	23(15.8%)
Chronic obstructive pulmonary disease	17(11.6%)
Congestive heart failure	15(10.3%)
Frailty	14(9.6%)
Chronic liver disease	10(6.8%)

Others	4(2.7%)
Comorbidities	
Mean number of comorbidities	5.4
Hypertension	93(63.7%)
Pressure ulcer	83(56.8%)
Cognitive impairment	76(52.1%)
Stroke	71(48.6%)
Anemia	62(42.5%)
Diabetes mellitus	53(37.0%)
Congestive heart failure	43(29.5%)
End-stage renal failure	41(28.1%)
Atrial fibrillation	32(21.9%)
Chronic obstructive pulmonary disease	30(20.5%)
Hip fracture	21(14.4%)
Clinical Characteristics	
Mean (SD) Abbreviated Mental Test score (max 10)	2.2(±3.3)
Mean (SD) Norton Risk for pressure sore (max 30)	10.8(±3.7)
Mean (range) Number of oral medications	3(0–16)
Mobility status: bed-ridden	63(43.2%)
Mobility status: chair-bound	42(28.8%)
Mobility status: walk with or without aids	41(28.1%)
Long-term naso-gastric feeding	63(43.2%)
Long-term urinary catheterization	21(14.4%)
Long-term oxygen therapy	23(15.8%)

Table 1: Baseline characteristics of patients in this audit (N=146).

failure (10.3%), frailty (9.6%) and chronic liver diseases (6.8%). Over 70% of the patients had very limited mobility (either chair-bound or bedridden). 85 of the 146 patients (58.2%) were verbally non-communicative. 139 of the 146 patients were assessed using the Abbreviated Mental Test (AMT) score, with the mean score of 2.2 (maximum score 10), of which 113 patients (81.3%) had a score equal to or lower than 5. The mean body mass index was 18.2 kg/m² and mean serum albumin level was 27.8 g/l.

The median length of stay of the last episode of hospitalization was 17 days (range 1-193 days) at SH, and 3 days (range 1-20 days) at PWH. 131 of the 146 patients (89.7%) died within 6 months of being enrolled into the EOL care program. Nearly half of the patients (71/146, 48.6%) died during the same admission for which they were enrolled into the EOL care program. 114 patients died at SH, 19 at PWH, 5 within the AED of PWH, and 8 at other hospitals.

Quality of EOL Care

To study the compliance rates of the five selected goals, case notes regarding the clinical conditions of patients in the last seven days of life were reviewed. However, 5 out of 146 patients were certified dead within the AED of PWH, 8 died in other hospitals, and case notes of 4 patients were missing, so only case notes of 129 patients could be retrieved and data ana-

lyzed. Table 2 summarizes the compliance rates of five selected goals. Two goals, including minimization of regular monitoring of vital signs and no blood taking, achieved over 70% compliance at SH, but 0% at PWH. The compliance rates of discontinuation of non-essential medications in SH and PWH was 46.4% and 47.1% respectively without statistically significant difference (p=0.961). Over 90% of the patients continued with their anti-platelet or anticoagulant agents, over 80% with their anti-hypertensive drugs, and over 30% received antibiotics during the last day of life. For the switching of essential medications to non-oral routes, the compliance rate in SH (63.4%) was lower than that in PWH (70.6%), but there was no statistically significant difference (p=0.564). The compliance rate of prescribing as-required intravenous or subcutaneous palliative medications was extremely low (<2%) in both PWH and SH.

Use of Futile Life-Sustaining Procedures and Treatments

Table 3 summarizes the number of futile life-sustaining procedures and treatments. All of these futile procedures and treatments were given in PWH, and none in SH.

DISCUSSION

In this study, we assessed and compared the quality of

	Overall (N=129)	SH (n=112)	PWH (n=17)	P-value
Discontinuation of non-essential medications	60 (46.5%)	52 (46.4%)	8 (47.1%)	1.000
Minimization of regular monitoring of vital signs	81 (62.8%)	81 (72.3%)	0 (0.0%)	<0.001
No blood taking	87 (67.4%)	87 (77.7%)	0 (0.0%)	<0.001
Use of as-required IV or SC palliative medications	2 (1.6%)	2 (1.8%)	0 (0.0%)	1.000
Switching of essential medications to non-oral routes	83 (64.3%)	71 (63.4%)	12 (70.6%)	0.787

Table 2: Compliance rates of five selected goals.

Example	Number of cases
Cardio-pulmonary resuscitation	6
Use of inotropic drugs for treatment of shock	3
Intubation	2
Non-invasive or mechanical ventilation	2
Fluid resuscitation for hypotension	2
Use of diagnostic Oesophago-Gastro-Duodenoscopy	1
Use of diagnostic abdominal paracentesis	1

Table 3: Examples of futile treatments in the last 7 days at PWH.

EOL care for older patients with non-cancer diagnoses under the EOL care program in the convalescence hospital vs. acute hospital by the compliance rates of five criteria, and the use of futile procedures and treatments. The results highlighted service gaps and areas for improvement in the EOL care program, particularly within the acute hospital. The compliance rate of discontinuation of non-essential medications was lower than 50% at both hospitals. These figures suggested that medications were less likely to be titrated according to the individual clinical conditions towards the end of life. Compared with 100% compliance rate reported in a similar study in a local oncology unit,¹⁴ the lower compliance rate in our study might have resulted from insufficient guideline and staff awareness during initial assessment. Minimizing the drug load by signing off relatively non-essential medications should be emphasized for the sake of comfort care in any medical unit.

It was also shown that essential medications for symptom control were less likely to be used at the acute hospital, for example, in the use of morphine. It was potentially associated with differences in the working culture between convalescence and acute hospitals. The concept of EOL care permeated throughout the convalescence unit of the convalescence hospital, so its clinical staff was better prepared to take care of the dying patients, especially in the aspect of symptom control.

Overall, the rate of using essential medications *via* non-oral routes in the last days of life was fair (63.4%). However, the rate of prescribing as-required palliative medications *via* intravenous or subcutaneous route was low in both hospitals, below 2%. It signified a potential increased risk of inadequate symptom control in the final phase of life. The frequency of vital sign monitoring was noted to be much higher at the acute hospital compared to convalescence hospital. It should be noted that frequent monitoring of vital signs may cause unnecessary dis-

comfort, emotional arousal and anxiety among patients and their family members. Furthermore, any abnormal findings would lead to further excessive investigations, such as blood tests, X-rays and electrocardiograms. Clinical staff should shift their attention from routine monitoring of vital signs to focus on symptom control, such as dyspnoea, pain, fever and restlessness. A higher priority should be placed on routine nursing care, including mouth care, skin hygiene, turning and assisted oral intake.

Two of our study patients underwent invasive investigations and procedures for the workup of malignancy (Oesophago-gastro-duodenoscopy (OGD) and abdominal paracentesis), despite the fact that they were unlikely to be a candidate for surgery, radiotherapy and chemotherapy, and their life expectancy was shorter than six months. Not only would the investigations not alter the treatment, they might also induce extra physical and psychological stress on the patients and their family members. Nonetheless, the DNR order was not equivalent to 'no-treatment' order, and it could be worthwhile ordering investigations but only if the focus was to improve the quality of life, such as blood transfusion for symptomatic anemia, or thoracentesis for symptomatic pleural effusion.

Despite being offered direct admission to the convalescence hospital when necessary, many patients were admitted to the acute hospital through the AED, because of acute medical deterioration. They often spent a few days at the acute hospital before being transferred to convalescence. As mentioned likewise in an article review,¹⁵ patients at the acute hospital were handled by many different physicians with variable clinical expertise in EOL or geriatric care. Interns were usually the first medical contact to deal with the symptoms reported by the nurses. It was not uncommon that some futile treatments were initiated by the interns or junior medical staff (e.g. as non-invasive ventilation, fluid resuscitation and ordering blood and imaging tests), although many of which were subsequently stopped by

the attending physicians. These often happened during non-office hours or the middle of the night. Another major problem was a generally poor quality of documentation for decisions or treatment plans, such as whether there should be escalation of treatment in case of deterioration.

The convalescence hospital had a palliative team with two hospice wards. It enabled medical officers to acquire more up-to-date knowledge in symptom relief for the dying patients and other healthcare staff to have more opportunities for receiving training in EOL care. Moreover, EOL and palliative care approach were often promoted at clinical seminars and case presentations. All of these initiatives made a significant impact on patient care in this study. In addition, the independent review on Liverpool Care Pathway (LCP) in the United Kingdom (UK) pointed out that a care pathway itself would not guarantee a quality palliative care. It only worked well if operated by well-trained, well-resourced, and sensitive clinical teams. Adequate training, education and resources should be offered to the front-line clinical staff on top of provision of guidelines with a view to increasing their motivation and self-efficacy in adopting the LCP, as well as enhancing the communication with the patients and their carers.¹⁶⁻¹⁸ Moreover, the attending physicians should document clearly the decision and treatment plan in advance, after discussing with patients and/or their family members, so the on-call colleagues were able to deliver a consistent care.

In Hong Kong, the law (Ambulance Ordinance) dictates that patients with cardiorespiratory arrest in the community must be resuscitated. CPR was therefore initiated in six patients, who were found to be in cardiorespiratory arrest, by the ambulance crew. To avoid this futile life-sustaining procedure, it was of paramount importance to enhance the communication between the hospitals and the ambulance service on the EOL care program through the use of Advanced Care Planning (ACP) forms. These documents would allow the patients or their proxies to clearly indicate the wish of life-sustaining treatment, such as intubation and CPR, in case of terminal illnesses, persistent vegetative state or in a state of irreversible coma. Moreover, the Ambulance Ordinance should be reviewed and amended, so that the DNR order for dying patients with an ACP could be respected by the ambulance crew. Professional development program in ACP for healthcare staff would be in place to promote their uptake of ACP.¹⁸ In addition, a detailed and clear documentation in the corporate electronic patient record about the EOL care plan could facilitate a better communication among healthcare providers even if the patients were admitted to different hospitals in Hong Kong.

LIMITATIONS

This study has several limitations. Firstly, in view of the retrospective nature of this study, some clinical information could not be retrieved from the case records, so the reasons for non-compliance were not fully evaluated in this study. Secondly, the quality indicators adopted in this study were modified from

the LCP, which was strongly recommended for reform by an independent panel in 2013.¹⁷ It was revealed that the LCP could not perfectly fit into each of the cases, and there was a risk of over-emphasis on the protocol instead of the outcome of EOL care. In fact, the quality indicators we adopted were found to be capable of reviewing how the EOL care services provided rather than its outcome. Measurement of outcomes by using the questionnaires filled out by clinical staff and the family carer should be included in further studies to enable a more comprehensive assessment on the quality of EOL care.¹⁹ Thirdly, it was difficult to justify whether palliative medications on patients were “essential” in a retrospective review, as fair justification could not be made simply based on WHO recommended drug list. It should be considered with individual patient clinical context. Lastly, this was a small sample size in a local hospital in Hong Kong, so the results may not easily be generalizable to other populations.

CONCLUSION

We found significant differences in the quality of EOL care for older people with non-cancer diagnoses between an acute hospital and a convalescence hospital in Hong Kong. Greater emphasis on specialist training and education, as well as allocation of resources is needed to improve EOL care. Since the completion of this study, our services have been redesigned to improve the EOL care for older people with non-cancer diagnoses at both hospitals.

ETHICAL APPROVAL

Our study has the necessary ethical approval. The approval reference is CUHK-NTEC CRE 2015.492.s.

CONFLICTS OF INTERESTS

The authors declare that they have no conflicts of interest.

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Opinion

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Challenges in Palliative Care Postgraduate Education in Latin America – Time for Collaboration

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On May 24th, 2014, the World Health Assembly (WHA) issued the resolution 67.19: “Strengthening of palliative care (PC) as a component of comprehensive care throughout the life course”,¹ which crowned the efforts of hundreds of professionals who have worked to extending the field of PC and making it available to everyone, throughout the continuum of care and across all levels. The ultimate goal of this resolution was to promote the relief of people’s suffering due to illness, as an integral part of health care, and to provide the human, physical and economic resources in order to attain this objective. To achieve this aim, the assembly encouraged the State Members, among other initiatives, to include PC as an integral component of education and training offered to health care providers (HCP), according to whether the educational need is basic, intermediate or specialty level. Therefore, providing better PC education in all three levels is an essential step to extend PC and to alleviate the suffering of people around the globe.

PC is an evolving discipline. A core set of learning domains have been identified as part of the PC competencies that HCP should have in order to provide relief of suffering.² These competencies include symptom management, assessment and treatment of psychological, social and spiritual needs, decision making and communication with patients and families, among others and should be acquired by HCP according to the level of training and to the type of specialty that they will work on.^{3,4} Although these competencies have a cognitive component, most of them also include a practical component. This practical component includes acquiring skills, attitudes and values as an essential part of the learning process in order to favor behavioral change. These abilities need to be taught not only through standard lessons, but through clinical modeling, including critical observation with feedback, role playing, mentoring and reflective practice.⁵ Guiding trainees in the process of reviewing and applying the evidence, learning how to communicate better and becoming clinical experts in this particularly sensitive field is now an extremely interesting, complex and demanding process for trainers.

In order to achieve the goal of extending PC proposed by the WHA, countries need trained HCP to deliver high quality PC and to teach the aforementioned competencies to both undergraduate and graduate students.¹ However, there is a lack of trained PC providers in Latin America and there are insufficient educational programs both at the undergraduate and graduate levels.⁶ Countries, national and international palliative care associations and NGOs have developed different strategies to deliver education in PC for HCP in this context. Some countries in the region are developing undergraduate PC programs to promote education at this

level, although it is unclear which educational strategies are the best ones.^{7,8} Other countries have developed Fellowships or Sub-specialty clinical training programs, Masters Degrees, Diplomas and on-line programs, many of which lack a hands-on component. Although this breadth of strategies provides different alternatives for HCP interested in acquiring PC skills, the quality of these programs are varied and the level of competencies developed by the trainees among these programs are extremely heterogeneous. Moreover, if we consider that teaching PC skills have an essential practical component, the fact that many of the training programs are only theoretical, implies that some trainees are obtaining sub-optimal education in PC.

The problem of getting high quality postgraduate PC training for HCP is particularly relevant for developing countries in Latin America. Most of the best programs are offered by institutions from developed countries with a long history and experience in the field of PC, with only few alternatives in our region (Colombia, Costa Rica and Venezuela among others). The current available local programs are unable to train the required number of HCP to supply the needs for the region.^{6,9} Usually the high quality programs in developed countries are mainly available for clinicians from the same country or region and are not always available for foreign clinicians. Some of the difficulties for international HCP in being admitted to the top PC clinical programs in developed countries include obtaining prior training certification, language and cultural barriers and lack of funding. Therefore, today most HCP from developing countries can aim to get only on-line training as their best option to learn competencies and skills in PC. The problem of limited training opportunities could be a potential barrier for achieving the goals proposed by the WHA in Latin America and could increase the inequality of the delivery of PC services between developed and developing countries.

A possible solution to overcome this gap could be to encourage and to facilitate the training in PC of HCP from Latin America at high quality institutions from developed countries which have the experience, knowledge and skills to provide this kind of advanced training. These recognized institutions could also offer mentorship, training and recognition or accreditation to develop clinical modeling programs in developing world centers. WHO, State members, local academic institutions and NGOs should work as facilitators to overcoming the certification, language, cultural and financial barriers and to promoting academic exchange. Another possibility could be to develop few high quality PC education centers in Latin America with the support of NGOs, local universities and internationally recognized academic leaders and institutions. These centers could take the leadership to educate HCP in PC within the region. Favoring international collaboration and enhancing academic exchange is an essential step to improve the training of regional PC providers. This exchange could also enhance mutual understanding of the different realities of illness related suffering around the world and to expand the knowledge of global palliative care. All these alternatives could be feasible and effective strategies

to overcome the inequality in training that currently HCP from countries in Latin America are getting and to throughout better education achieve the goal of strengthening PC as a component of comprehensive care throughout the life course in our region.

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CONFLICTS OF INTEREST

The authors have no conflicts of interests to declare.

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Telephone versus Face to Face Palliative Care Consults during Referral

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ABSTRACT

Introduction: Palliative care aims at ameliorating patients and families suffering when they are faced with life-limiting illnesses. It involves symptoms management as well as psychosocial, spiritual support. As such, proper communication between clinicians taking care of the patient is an important aspect of this care. Studies have shown that errors in communication are common and relevant in palliative care as they negatively impact on the quality of care provided. The service at Aga Khan University Hospital, Nairobi (AKUHN) provides both in and out patient consult services. Primary physicians to patients consult the palliative care team *via* telephone models as well as face to face talks. There is a lot of literature regarding patient/family member consultation with a doctor but little has been done on understanding the efficacy of doctor to doctor telephone discussion on a patient being referred from one service provider to another.

Objective: The aim was to assess the adequacy of information regarding the patient given in telephone consults *versus* face to face consults during the referral process.

Methodology: This was a cross-sectional study. 60 consults to the palliative care team were assessed, these were consults received over a period of 4 months; 36 were telephone consults and the rest face to face. The information was assessed for inclusion of the following details: I) name II) age, III) gender, IV) longevity of illness, V) ward/clinic location, VI) Patient's diagnosis, VII) reasons for referral, VIII) current treatments, IX) patient's knowledge of their diagnosis and prognosis, X) family's knowledge of diagnosis and prognosis and XI) patient's and family's knowledge of referral to palliative care.

Results: Overall, there are more missed characteristics of a patient in a telephone consult compared to a face to face consult. The most missed characteristics in both types of consults were name, patient and family knowledge of referral, patients' and families knowledge of diagnosis.

Conclusion: It is evident that a telephone consult is less informative than a face to face consult. It is therefore important to have a face to face discussion on a patient after telephone consultation. It is also evident from these findings that doctors are still poor in the aspects of communicating with patients, their families and also among themselves and more need to be done to improve this.

KEYWORDS: Palliative care; Telephone consults; Communication; Palliative care consultation.

INTRODUCTION

The technology of telemedicine has been used for over 20 years and may be useful in palliative care for the patients lacking access to medical services and the use of mobile telephony has been recommended as an easy way of providing timely and quality assessment of patients in palliative care.¹ In palliative care, proper, timely and sensitive communication is recommended in order to offer high quality care to patients and family's. Understanding the patient's and family's knowledge of the disease, prognosis and treatment guides the palliative care team to adequately plan care for the patient. One of the key components in palliative care is communication and mobile telephony technologies can be an effective way to support communications between clinicians.² There is need to quantify the adequacy of this mode of communication compared

to the traditional face to face model as its use is more applicable in palliative care due to the fact that mobility for these patients sometimes is limited.³

There is lack of information about the use and adequacy of telephony communication for palliative care referral and the general outcome on their use. This is particularly urgent given the great and accelerating penetration of information technologies, especially mobile phone and Internet connections in developing countries, which is creating large numbers of potential users that could benefit from well-designed systems to support health in general and palliative care in particular. The availability of effective ways to communicate with patients and caregivers, along with effective Health interventions or applications, might significantly improve the availability of palliative care especially in underserved populations and in poor resource settings.² However, communication errors in telephone medicine can result in adverse outcomes ranging from inconvenience and anxiety to serious compromises in patient safety, identity and quality of care.⁴

METHODOLOGY

A cross-sectional survey was performed based on registration of referral consults to the palliative care team. The policy is that the primary doctor calls, talks or writes to the palliative care team when a patient meets the palliative care referral criteria and thus requires access of this service. There were a total of 82 consults during the 4 months period of study, June- September 2015, with 60 of them being face to face and telephone consults combined. Of the 60, 36 were telephone consults to the palliative care team while 24 were face to face. The 22 patients sent to the palliative care team with a referral form or note were excluded from this study as the pre-prepared form has details that guide the referring doctor on the information to fill in. The details given by the referring doctor, *via* face to face or telephone consult, were recorded verbatim. There was no prompt for more details during the initial consultation discussion. We did not assess the time taken for a consult as the primary research concern was the adequacy of information given by the referring doctor. The

information given by the referring physician was assessed for the inclusion of the following patients’ characteristics using a checklist developed by the researcher (Table 1):

- I) Name
- II) Age
- III) Gender
- IV) Longevity of illness
- V) Ward/clinic location
- VI) Patient’s diagnosis
- VII) Reasons for referral
- VIII) Current treatments
- IX) Patient’s knowledge of their diagnosis and prognosis
- X) Family’s knowledge of diagnosis and prognosis
- XI) Patient’s and family’s knowledge of referral to palliative care.

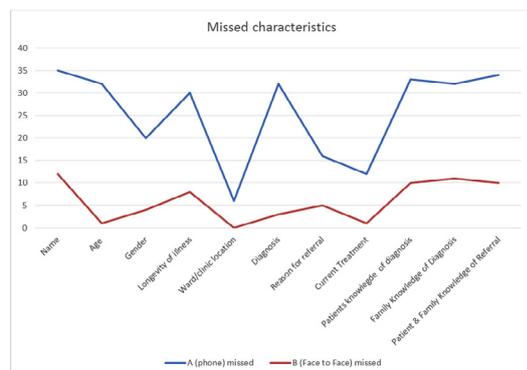
RESULTS AND DATA ANALYSIS

Overall, there are more missed characteristics of a patient in a telephone consult compared to a face to face consult. The most missed characteristics in both types of consults were name, patient and family knowledge of referral, patients’ and family’s knowledge of diagnosis (Graphs 1A and 1B). Significantly, 89% (n=32) of the phone consults did not mention the age of the patient compared to only 4% (n=1) of the face to face talks. The non-verbal prompt by the member of the palliative care team during a face to face consult could explain the reason why the age of the patient is largely given during this type of discussion. The location of the patient was detailed in all face to face consults and 83% of phone consults. This is therefore the least missed patient characteristic in this study in both types of consults being considered. This may be due to the fact that primary doctors usually call the palliative care team after reviewing a patient and thus the physical location is usually indicated. 79% of all consults had the patient’s name not mentioned during the entire conversation in the referral process. The fact that doctors consider the location of the patient as an important identifier is a contributing factor to this scenario. There could also be an

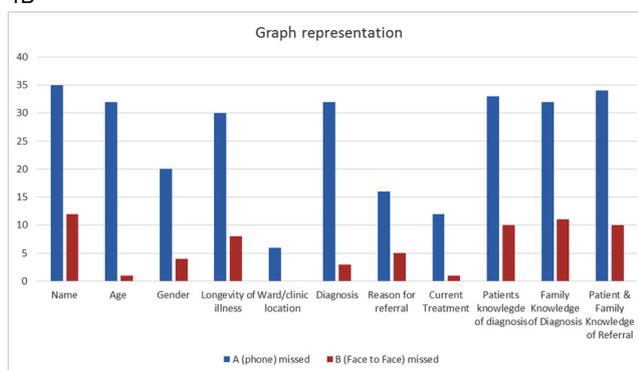
Characteristics	A (phone) missed	B (Face to Face) missed
Name	35	12
Age	32	1
Gender	20	4
Longevity of illness	30	8
Ward/clinic location	6	0
Diagnosis	32	3
Reason for referral	16	5
Current Treatment	12	1
Patient’s knowledge of diagnosis	33	10
Family knowledge of diagnosis	32	11
Patient and family knowledge of referral	34	10

Table 1: Missed number of patient’s characteristics per type of consult.

1A



1B



Graphs 1A and 1B: The missed patient characteristics in the consults.

assumption that the palliative care team being consulted will be able to generally locate the patient and thus know their name once they arrive at the patient’s station. 88% of phone consults did not mention the diagnosis of the patient, a significant challenge in the provision of quality care as the diagnosis of a patient is a very important guide on types of challenges that they may be facing and in clinical decision making.

DISCUSSION

The findings in this study reveal that during telephone consults, significant patient information can be missed. It is evident that telephone consults are not as adequate as face to face consults in palliative care. As technology grows, consultations *via* mobile telephony will increase and thus there is bound to be a significant challenge in the adequacy of information passed from referring clinician. Although telephone consultation has been hailed as time saving and a more modern method of communicating, it has also been noted that doctors behave in a less patient-centred way on telephone and at the same time, more biomedical and less psychosocial or affective information is exchanged.⁵

It is recommended that the “attending health care practitioner” should provide the patient and family with a) information regarding palliative care and end-of-life options appropriate to the patient, and b) information and counseling regarding prognosis and reason for consulting the palliative care team.³ This should be based on the patient’s clinical and other circumstances; and the patient’s reasonably known wishes and beliefs. The “attending health care practitioner” should make clear to the patient and/or to his/her authorized health care decision maker that decisions concerning options rest with the patient and/or his/her decision maker. These discussions need to be clarified with the palliative care team member who is being consulted.

A significant number of consults do not identify patients by names both in face to face and telephone talks as is evident in this study. Identifying patients by their names when talking to them or when discussing their illness with colleagues

is important, a show of respect and also individualizes patient’s diagnosis, prognosis and plays a crucial impact in the quality of communication between health care providers, patients and families.⁶ In a hospital setting where there can be multiple patients with similar illnesses at the same trajectory of illness, it would be disastrous to mistake the patient who was referred for care. It is ethically recognized that patients need to be identified using at least 2 aspects, most importantly being their names.

The study reveals that most doctors do not provide information regarding the longevity of illnesses and stage at which it is. At the same time, both models of referral experienced a significant miss on patients and families knowledge of disease and their being informed of referral to palliative care. This could be due to the fact that physicians themselves still experience stigma when it comes to issues regarding end of life and they might find it challenging to even inform their patients about prognosis leave alone need for supportive care service from the palliative care team. Giving bad news remains a big challenge for effective and efficient communication in medical practice; this negatively impacts on the quality of care provided.⁷

CONCLUSION

Patients and their families should be informed by the primary consultant that the patient is being referred for palliative care. It is important that when making the referral, the following information is provided: Patient’s name, Patient’s diagnosis, Patient’s location and their knowledge of the illness. It is evident that a telephone consult is less informative than a face to face consult. It is therefore important to have a face to face discussion on a patient after telephone consultation. It is also evident from these findings that doctors are still poor in the aspects of communicating with patients, their families and also among themselves and more need to be done to improve this. The findings of this study mirrors¹ findings that bedside or face to face consultations have a surplus value compared to telephone consultations. More rigorous studies should be undertaken to study the merits of the different modes of consults. Familiarity with common errors in telephony consults would decrease the

likelihood of referring physicians making omissions regarding important patient's information.⁸

To enable the palliative care team provide quality care from the first moment of contact, it is imperative that full information regarding patients is provided and this can be made possible by educating doctors on communication skills especially when using mobile telephony to cross-consult. It would also be useful to develop mobile apps and tools that can be used for doctor to doctor communication regarding a patient. This way, missing crucial patient data will be minimized. A developed referral form that requires to be filled by the referring clinician even after telephone consult to the palliative care team will also enhance adequacy of information provided.

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