

Caring for the dying in a developing country, how prepared are we?

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ABSTRACT

End of life care is framework to allow for a peaceful, comfortable and dignified death while considering the patients' personal and religious values, bioethics and knowledge of the disease process. A well planned end of life pathway should allow for the flexibility to shift from an active (or aggressive) treatment approach to one of comfort and care when initial interventions have failed. The need for this pathway is most apparent in the intensive care setting. Implementation of a pathway will face various challenges due to religious and cultural beliefs, education of healthcare providers to carry out difficult discussions and larger socioeconomic implications. Clear medico-legal framework will be required to support this pathway. In conclusion, an end of life pathway tailored to our local needs is the way forward in allowing for dignified death of terminally ill patients; this will require the active participation of medical societies, religious leaders, healthcare providers, patients and their care givers.

KEY WORDS:

End, life, pathway, dying, dignity

INTRODUCTION

It has been a decade since the Malaysian Medical Journal first introduced the idea of palliative care in medical practice, yet many practitioners are still unfamiliar and inadequately trained in dealing with end of life issues. Therefore this article aims to help reignite the discussion within the medical community and patients about the end of life pathway for terminally ill patients and to highlight the challenges in introducing the end of life pathway in Malaysia.

Statistics

In 2000, the number of Malaysians aged 60 years and above was estimated to be 1.4 million and projected to increase to 3.3 million by the year 2020. The percentage of the population 60 years and over has also increased over the years - 5.2% in 1970, 6.3% in the year 2000 and is expected to be 9.8% of the population in 2020. Between 1990 and 2020, the population of Malaysia is expected to increase from 18.4 million to 33.3 million - an increase of 80%. The elderly population is expected to increase from 1.05 million in 1990

to 3.26 million over the same period, an increase of 210%.¹ With aging comes the burden of age-related ailments such as cancer, heart disease, dementia etc.

The top two ranked uncertified medical deaths in Malaysia are due to old age (above 65 yrs old) and cancer with 59.4% and 6.9% respectively.² These figures indicate that a large number of elderly and cancer patients die at home or institutions outside hospitals due to malignancy or frailty. Up to now, accurate details of cancer epidemiology in Malaysia are not available and the incidence of cancer is merely based on small scale cancer registries. The only updated regional mortality data available is by GLOBALCAN in 2012 reported that up to 22,000 people (crude rate of 73.9/100,000 population) died from all types of cancer excluding non-melanoma skin cancer in Malaysia annually.³ Although this data may be under reported, it remains the most reliable cancer data available. In addition, we lack data on the pattern of death for cancer and its associated demographics such as age, gender, cancer type, stage of cancer etc, to guide us in allocating appropriate resources and services to the terminally ill.

In comparison, the National Hospice and Palliative Care Organization (NHPCO) reports on Hospice Care in America and noted that in 2012, an estimated 1.6 million patients received services from hospice.⁴ Medicare, which provides health coverage for residents above the age of 65 years in the United States, showed that the overall proportion of Medicare decedents accessing three or more days of hospice services in 2007 had increased to 30.1% from 18.8% in 2001. While the number of Medicare decedents with a cancer diagnosis that had accessed three or more days of hospice care, grew from 36.6% in 2001 to 43.3% in 2007. A similar increase in hospice use was also noted for decedents with dementia. In 1982 the United States Congress created the Medicare hospice benefit, allowing for such services for terminally ill Medicare beneficiaries with life expectancies of six months or less "if the disease runs its normal course" on an inpatient and/or outpatient basis.⁵ Funding for end of life care in Malaysia comes in the form of government grants and public fundraising as per the Malaysian Hospice Council.⁶ Much of hospice or end of life care for the terminally ill cancer patients in Malaysia is available to inpatients, unfortunately

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Table I: Three Ethical Principles highlighted in the treatment and care towards the end of life guidance by the General Medical Council (4)

It is the doctor's obligation to:	
1)	to show respect to the human life
2)	To protect the health of patients
3)	To treat patients with respect and dignity
4)	To make the care of patients their first concern

Table II: The four ethical principles to aid decision making based on the burden of proportionality

Principle	Definition
Autonomy	An adult with the capacity to understand his/her medical problem can refuse any treatment or test regardless if it is simple, safe or risk free.
Beneficence	Physicians have the responsibility to act on the patients best interest
Non-maleficence	To do no harm
Justice	Fairness is expressed as a notion that similar person should be treated similarly.

that only covers 10% of the patients in need of hospice care. This does not include patients dying of other terminal illnesses. In comparison, our southern neighbours have hospice coverage available to 60% of their terminally ill cancer patients.

The End of Life Pathway

The Oxford medical dictionary describes death as the absence of vital functions or permanent cessation of heart beat.⁷ As medical practitioners, it is inevitable for many of us to focus on preserving life when dealing with a terminally ill patient while skirting the issue of death and dying. Despite all the detours taken to avoid dying, we will arrive at the crossroads of the limitations of modern medicine and nature's timeline. While we grapple with the path ahead, it is easy to lose focus of the person dying and the family struggling to come to terms with their loved ones slow, and sometimes painful demise.

The New Hippocratic Oath has stated the need to recognise the value of human life and that prolonging life is not the only aim of healthcare.⁸ Therefore taking the Hippocratic Oath into consideration, there will be times where we will have to hang our stethoscopes when all active medical intervention has failed, and allow the patient a peaceful, comfortable and most importantly dignified death. The way we care for the dying patient highly reflects on our morals, beliefs and the value we place on life. The end of life pathway is a subset of palliative care when a patient is certain to be in a progressive state of decline.⁹

In its essence, the end of life pathway simply means a framework or guidance for health care professionals in order to allow a peaceful, comfortable and dignified death for the terminally ill patient. This must be in line with the patients' personal values, religious or cultural beliefs and medical knowledge of the disease process.¹⁰ In the United Kingdom, the end of life pathway (through the Liverpool Care Pathway) has long been available due to the recognition of the complexity in caring for the dying.¹¹ It highlights three pertinent principles a doctor should take into consideration when making decisions pertaining to the end of life of a patient (Table I). The biomedical model of ethics pertaining to this care pathway is dealt with later in this article.

The Liverpool Care Pathway (LCP)

The LCP developed by the Marie Curie Palliative Care Institute in Liverpool is a framework of good practice aimed to improve the care of the dying in the last hours or days of life by taking into consideration the physical, physiological, social and spiritual needs of the patient.¹² The LCP does not seek to replace clinical judgement and requires a multidisciplinary team (MDT) approach for clinical decisions, management plans and regular assessments. Decisions are made based in the patients' known wishes and/or best interest following discussions with the surrogate. The LCP has been recognised by the National Institute for Health and Clinical Excellence (NICE) for its role in the dying patient and is considered the gold standard of care applicable from a hospital setting to hospice.¹³ In short, the LCP was a system of guidance and documentation to allow for specialized palliative care treatment to be managed in a general medical setting. However the LCP's stand on nutrition, antibiotics and hydration of the dying patient has been its weakest point. The LCP had an expectation for artificial hydration and nutrition to be stopped.¹⁴ After almost two decades of the practice of the LCP, in 2012 the system came under public scrutiny for the above reasons and was finally withdrawn. The Neuberger Report highlighted that the failure of the LCP was due to the failure of the care pathway rather than the practitioners implementing the LCP.¹⁵ Mackintosh in his publication in the *British Medical Journal* was of the opinion that the demise of the LCP has left the UK practitioners with no bench-mark for end of life care.¹⁴

Aspects of the End of Life Pathway

In establishing a care pathway for the dying, there are many factors that need to be considered, as follows:

1. An ability to recognise dying or imminent death: Kennedy *et. al* 2014 have eloquently summarised the literature findings on diagnosing dying and have concluded that it is a rather complex process with many uncertain clinical (biopsychosocial) indicators.¹⁶ However, progressive inability to carry out his/her activities of daily living (to becoming fully dependent on others) coupled with altered conscious level, refusal to drink or eat, physical signs such as laboured breathing and reduction in urine output are taken as signs that death is imminent.

However, many medical practitioners may miss these subtle signs and instead regard the patient as being depressed or withdrawing from social interaction.

Certain diseases like dementia and organs failure may follow different diseases trajectories as compared to cancer. Making recognition of imminent death even more complex. At times, the acute worsening of symptoms may be due to a transient factor such as coronary artery disease, pneumonia or urinary tract infection, which can be treated with anti-platelet therapy or antibiotics.

2. Once a diagnosis of imminent dying is made, the aim of care shifts from an active, aggressive approach to a symptom management and comfort-focused approach. On-going communication between the MDT and family members (or care givers) should be the mainstay of the end of life pathway. The family members should be invited to be part of the caring process and be informed of the patients' progress at pre-determined intervals. Medical, physical, psychological or spiritual needs of the patient and their care givers should be addressed in order to achieve a successful partnership in caring for the terminally ill.
3. Care of the dying should be spiritually and culturally appropriate for patients and their significant others.¹⁷ Therefore in order to establish a reasonable care pathway for the terminally ill, medical knowledge with evidence based practice and clinical experience alone are not sufficient. Healthcare professionals directly or indirectly involved in the pathway should be culturally aware and have adequate exposure to managing patients from different cultural backgrounds. Some understanding of care prior to death and after death may reduce the psychological burden on the family members.
4. Ethical dilemmas surrounding end of life care such as futile treatment involving life sustaining measures of hydration, nutrition, mechanical ventilation, antibiotics, blood products transfusion, cardio-pulmonary resuscitation (CPR) and intensive care admission should be addressed with care as it may cause undue stress and create animosity between the MDT and family members. Appropriate local guidelines should emphasize the need for an effective communication process and appropriate documentation.¹⁸ Ideally, advanced medical directives created by the patient should be used as a guide on how these issues should be handled. However, advanced medical directive has yet to have any legal standing in Malaysia at this time. Therefore, effective and ongoing communication between the patient, their appointed surrogates and the MDT is important in order to understand the patients' wishes and to avoid disagreement.¹⁹ However, if a legally complicated or an ethically suspect situation arises, legal advice should be sought.

Pharmaceuticals in End of Life Care

The pharmaceutical approach includes addressing symptom control and pain management at end of life. Common symptoms include pain, breathlessness, nausea, headache,

insomnia and anorexia. Appropriate medications when available should be offered to relieve these symptoms.

The use of stronger opioids at end of life is necessary in many cases. Opioids, especially in injectable form, may be a better option due to its faster onset of action and the patients' general condition such as poor mentation, weakness and dysphagia. Parental opioids are readily available in most government or private hospitals and mobile hospice services throughout Malaysia. In a hospital setting, parenteral opioids can be administered by junior doctor and nurses (with supervision) via subcutaneous route at a titrated dose and later a cocktail of analgesics/sedatives/anti-emetics medications (subcutaneous/intravenous) if needed for maintenance.

Other more potent opioids that are available in certain regions of Malaysia include transdermal fentanyl patches (12mcg/h, 25mcg/h and 50 mcg/h), oxycodone immediate (IR) and sustained release (SR) formulations and injectable Morphine Sulphate. Some patients already are on opioids for pain relief are encouraged to continue taking their current pain medication with a breakthrough regime included if needed (via IR formulation).

Tertiary and secondary hospital with pain service via anaesthesia and/or palliative medicine service would be able to manage pain and symptoms experienced by patients at end of life. However, patients at smaller district hospital or out of reach rural areas may face some difficulties in these aspects.

Other medications commonly used at the end of life are sedative (psychothropic medications), anti-nausea, and anti-muscarinic (for oral secretions) agents, which are readily available in most medical facilities except private general practitioners' clinic. In conjunction with the availability of these medications, education of the appropriate medications for specific symptom control, correct dosing and titration/maintenance will need to be emphasized to all medical professionals with the guidance of the Palliative Care service.

Intensive Care Dilemma

In the United States, approximately 20% of all deaths occur during or after an admission to an intensive care unit (ICU) with most of these deaths preceded by a decision to withhold life-sustaining treatment.²¹ This decision is usually made when the goals of care cannot be achieved following a trial of aggressive life-sustaining interventions such as mechanical ventilation (life support/ventilator), heart pumps etc.¹⁶

Unfortunately, due to acuity of illness, the goals of care are frequently not addressed with healthcare surrogates or not agreed upon due to religious or personal beliefs. In addition, a lack of advanced directives or poor understanding of the disease process frequently places an undue burden on surrogates to help with decisions on goals of care. Unless the goals of care can be agreed upon, the patient tends to bear the cost of this uncertainty, taking away dignity and comfort in their final moments.

The dilemma faced in the ICU is a reflection of the long road ahead to incorporate and normalize end of life discussions as part of routine healthcare. Each known chronic medical problem such as diabetes, heart disease, chronic obstructive lung disease, represents a missed opportunity to talk about the only certainty in life, death (not taxes). In the United States starting 2016, medical practitioners will be reimbursed by Medicare for their services when carrying out end of life discussions during outpatient visits.

Legality and Ethical Dilemma

Decision making by healthcare professionals must comply with the principles of the Human Rights Act whereby everyone's right to life is protected by law.²² A legal framework must be created to support the introduction of the end of life pathway in Malaysia. The current American model can be taken as an example to create a medico-legal framework here in Malaysia.

End of life decisions should evolve around the four ethical principles as defined in Table II. All patients have the autonomy to make an informed decision on their treatment outcome. However, in end of life care, the adult patient in question may not have the capacity to do so. Therefore, adult patients with no capacity and no advance directive either via proxy or living will, decisions are based on the knowledge of clearly expressed wishes. If there is no clear expression of wishes then the next best basis on which to act is based the best interest of the patient with beneficence in mind. However, in cases where there is a dispute on capacity of the patient to make decisions, lacking clarity or disagreement between the care team and surrogate, health care professionals may consider engaging the local ethics committee. In the United States an ethics committee is used for cases where the patient is not an adult but has the capacity for an informed decision (for children less than 18 years), there is no clearly stated wishes on the part of the patient i.e. no living will/health proxy/Do Not Resuscitate (DNR)/Do Not Intubate (DNI) orders and if the caregivers/family are split or in disagreement about the nature of care. A court order can be sought if there is still lacking clarity even after consulting the ethics committee.

Some patients may opt to have a living will or advance medical directive which is a written document outlining the care desired by the patient especially if the patient is lacking a health care proxy. It should address the patients' wishes to maintain/withhold/withdraw life sustaining treatment in the event of terminal disease/persistent vegetative state/DNR/DNI orders are based on patient's preference regarding CPR and intubation.²³ This is where the treating physician or oncologist may step in to play a pivotal role to advise a patient to prepare a living will or appoint a healthcare proxy with regards to end of life care once a diagnosis of a terminal disease is confirmed.

Euthanasia is illegal by law in Malaysia and in the United States with the exception of Oregon, Washington, Vermont and California (physician assisted suicide). Many will often confuse the end of life care as an act of euthanasia. However these two are very different concepts. Euthanasia involves the administration of lethal agents with intent to end one's life.

While in end of life care for the terminally ill, no lethal medications are administered, only medications for therapeutic (pain and suffering) purposes are administered. As eloquently put by former U.S. Supreme Court Chief Justice Rehnquist, "It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient's death if the medication is intended to alleviate pain and severe discomfort, not to cause death".²⁴ End of life care may also involve the withdrawal of non-curative treatments such as antibiotics, mechanical ventilator, hemodialysis, vasopressor medication, whereby the focus of care shifts towards pain control and comfort with medications prescribed to relieve pain and suffering.²³

While an argument can be made that sedatives and analgesics administered to reduce pain and suffering may hasten death, this has not been proven in clinical studies.²⁵⁻²⁷

Challenges for End of Life Pathway in Malaysia

An end of life pathway for the terminally ill patient will require a paradigm shift to allow for a dignified death in Malaysia.

Having practised medicine in Malaysia and abroad, the authors would like to highlight the possible challenges facing the introduction of the end of life pathway guidelines in Malaysia.

Firstly, Malaysia is young country with multicultural and various religious beliefs, it may be against certain religious beliefs to 'give up' on the living and allow them to die, albeit peacefully. This leads to the need for an effective system to win over healthcare providers, governors of healthcare and most importantly the public in the form of guidelines for the end of life pathway.

Secondly, educating health care practitioners on the availability, conduct and benefits of such pathway is of great importance. This is to prevent a misuse or lack of use of the system due to inadequacy of understanding or training.

Next, healthcare is a resource intense endeavor especially if the resources are poured into new technology while ignoring pain and suffering. So after 10 years the time has come for a progressive end of life pathway that should be made available under the Clinical Practice Guidelines by the Academy of Medicine of Malaysia. Moreover, there should be timely review of the pathway to monitor and ensure its effective implementation and introduce improvements in accordance with new clinical evidence and views from patients, their family and religious authorities.

Finally the pathway application does not only end at hospital based healthcare facilities but also community based hospice and respite homes. As of today, there are twenty-three hospice and respite providers registered with the Malaysian Hospice Council; while Hospice Malaysia and MHF Hospice are independent providers concentrated in larger townships. These institutions fall short in providing for the 25,000 palliative beds needed for cancer patients, as estimated by the Malaysian Hospice Council. Therefore, there

is a need to boost community palliative services especially in smaller districts as the national coverage for community palliative care is a mere 10% compared to 66% and 80% of Singapore and New Zealand respectively.⁶

CONCLUSION

An end of life care pathway is the step forward for a more comprehensive healthcare delivery model in Malaysia. Such an effort will require active participation of not only the government but also healthcare institutions and medical professionals and patient advocacy groups. In keeping with the words of Henry Ford, "If everyone is moving forwards together, then success takes care of itself".

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