REVIEW ARTICLE

IS THERE ‘A GOOD DEATH’ AMONG CHILDREN WITH LIFE LIMITING ILLNESSES?

Fahisham Taib

Department of Pediatrics, Universiti Sains Malaysia, Malaysia

Keywords: Good Death, Bad Death, Death among Children, Palliative Care
Corresponding Author: Fahisham Taib, Department of Pediatrics, Universiti Sains Malaysia, Malaysia
Email: fahisham@kk.usm.my

Introduction

Many people discuss their journey of life but none would dare to speak about the journey of death. Though death is considered a certainty in everyone’s life, the subject remains a taboo topic in our community.

Medical care especially among dying patients with life limiting conditions, has evolved from curative to palliative-driven care. Palliative care focuses on holistic care involving psychosocial intervention, spiritual support, symptom control, advanced care planning and bereavement support. Ensuring a ‘good death’ especially in palliative care settings can be a challenging task. Poor quality of care is as a result of lack of palliative care knowledge and uncertainty of disease progression and trajectory. Healthcare professionals face difficulties in discussing patient’s prognosis due to inexperience in managing patients with terminal illness and uncertainty of the approach. Hence, the journey of death becomes as a lonely personal journey in the closing chapter of the patients’ life.

‘A Good Death’

Death is defined as non-functionality, irreversibility, universality, causality and personal mortality. However a good death has been interpreted in many different contexts. Some relate a good death as the actual peaceful event of death at a fixed time. Others perceived it as an acceptable way of a dying process with complex sets of preparation and relationship towards the end of life. The process of dying is related to receiving mutual care, support and loved by the family, resolving ‘unfinished’ business and mitigating the discomfort and loneliness before death. Clinicians are required to recognize patients who need end of life care with an honest discussion. However, the paradox of achieving good death without pain and suffering, despite continuous denial of death and living with false hope still exists. Good death means making use of the ‘final hours’ by spending meaningful time with the loved one. One study described good death as one which is free from suffering, in good accord with the patients and families wishes and consistent care with clinical, cultural and ethical standards. However, Kehl et al added attributes for good death which are – being in control, being comfortable, have a sense of closure, trusting to health care providers, recognizing impending death, leaving legacy, minimizing burden for the family, optimizing relationship, recognizing belief of dying patient, honoring values, caring for
family members and acknowledge the appropriateness of the death. In addition, the Debate of the Age Health and Care Study Group (1999), suggested that a good death is related to various factors (Table 1) including dying with dignity.

To know when death is coming and to understand what can be expected.
To be able to retain control of what happens.
To be afforded dignity and privacy.
To have control over pain relief and other symptom control.
To have choice and control over where death occurs (at home or elsewhere).
To have access to information and expertise of whatever kind is necessary.
To have access to any spiritual or emotional support required.
To have access to hospice care in any location, not only in hospital.
To have control over who is present and who shares the end.
To be able to issue advance directives which ensure wishes are respected.
To have time to say goodbye, and control over other aspects of timing.
To be able to leave when it is time to go and not to have life prolonged pointlessly.

Table 1. Factors considered as good death (4)

Due to lack of palliative care specialists worldwide, majority of doctors are considered as the main caregivers for the patients requiring palliative care service. It is the responsibility of every single physician in this world to ensure adequate standard of palliative care given to patients who needed it most. In developed nations, hospice has become an established institution to care for the terminally ill patients. The West has developed major pathways, guidelines and protocols to improve care and quality of life of these patients. In contrast to developing nations, the opinions are different. With no major resources or centres for palliative care, every doctor should know how to deal with life-limiting condition according to the demands and expectations. Many of the patients are left in the community with inadequate medical care and commonly being care by the inexperienced family members with the help of alternative medical practitioners.

Terminally ill patients often have complex medical and psychological symptoms attributed to his or her illness. Hence, identifying psychosocial and spiritual details is as important as managing the patients medically. Detailed management of physical, psychosocial, emotional and spiritual aspects are considered as holistic palliative care approach. The basis of palliation should not only be focused on the patients alone, but also supports the family members. The dying person and relatives should be asked what they feel or want, and what they consider to be culturally and traditionally appropriate. The patient-centered approach should be individualized and specified towards what is best for his or her dying process.
Palliative care is often seen as final stage care for terminally ill patients. It offers the best quality of care focused on relieving the suffering and patient’s needs, especially of those with early diagnosis of chronic illnesses or at terminal stage of the disease process. All health care professionals, regardless of the setting, should be equipped with adequate knowledge of care for the dying patients either in hospital or community settings. As clinicians, updated knowledge and education should include having own assessment tools, experience in clinical assessment and management, collaborative effort with multidisciplinary teams and providing support to family members psychologically. Interventions may also cover financial support or respite care for caregivers; recognizing mental ill health and spiritual input according to cultural and ethnical diversity. This integrative palliative care input requires a physician incorporating the multi-aspects of management during the acute and critical phase of the illness, by understanding the trajectories of the disease and considering their multisystem approach.

Breaking bad news and decision making are difficult subjects when dealing with life-limiting condition patients. It is still considered ‘strange’ to talk about death, even if the patients know the irreversibility of the disease outcome. Patients still have reservation to speak about this important topic. Many of health professionals avoid discussion on ‘death’ due to personal guilt, hopelessness, uncertainty about patient’s reaction, attachment to patients and feeling the inability to help. Effective communication is an essential part of the approach during this distressing time. In preparing patient to face death, physicians has to be ‘open’ in discussing options at the final hours of care, which may include withdrawing care, withholding treatment and withdrawing all active resuscitation.

The communication channel does not end here. Family members have to be told with empathy and sensitively. Every family is different in the approach and choices given to them. Family also needs to know that support is available and continued into bereavement period.

Education is part of the learning process in palliative care. However, palliative care emphasizes comfort care as opposed to curative care, in the modern medical fraternity. Priorities are aimed at relieving physical pain and to ensure patient can function as normal as possible. Physicians should be able to build a long lasting relationship with trust, to discuss personal matter openly according to patient’s values, wishes, needs and cultural differences. This can be done through adequate training, exposure and education targeted at medical practitioners. Education nowadays plays a vital role in disseminating knowledge which leads to national empowerment of volunteers and health care workers. The Liverpool integrated care pathway for dying patients is one of the excellent examples and has become the role model for ‘good care’.

There are many barriers that prevent healthcare professionals from having conversation regarding death and dying between the patients and the family. The main obstacle related to diagnosing dying patient with certainty, when there is disagreement between health care professionals. Mixed or contradictory decision-making will lead to poor patient’s management and care thus leading to ‘bad death’. It is usually very difficult to determine the passage of the time in cases of chronic illnesses. A pragmatic approach should be offered to resolve these issues. The knowledge of disease trajectories will aid in diagnosis and accurate estimation of
life before death. Hands-on experience in the hospice provides an understanding of the holistic approach when dealing with terminally ill patients.

Some patients still pursue unrealistic goals or futile interventions that may result in poor quality of care for terminally ill patients. Physicians need to recognize key symptoms and signs which may originate from the disease process or complications or even psychological elements. Majority of these patients still harbor hope of cure. Physicians often find themselves in limbo, due to unrealistic patient’s request. This can be resolved by informing the patient earlier regarding their health status. Patients appreciate knowing the reality that they are dying. There are also concerns regarding end of life care. Many would request the withdrawal of active resuscitation to die in peace and with dignity. Fear of death can be due to uncertainty of cultural, spiritual and medico-legal consequences.

Physicians may also face difficulties if patient and family are unaware that death is imminent. To resolve this, one ought to discuss the matter openly. Patient and family may lose trust in the doctor if his or her condition deteriorates without acknowledgment that this is happening especially in sudden event of death, and there is limited preparation time to face death. Some patients may also die with uncontrolled symptoms, leading to a distressing and undignified death. This is referred to ‘bad’ death. The treatment plan should be based on goal of care and avoiding unnecessary interventions. A ‘Do Not Resuscitate’ (DNR) order should be in placed to avoid unnecessary resuscitation and admission to intensive care.

Cultural and spiritual needs are rarely studied by doctors. Universal approach may not be appropriate if the patients have specific request based on religion, spiritual and psychological prior to his/her demise. One will need to learn different cultural spectrum to understand better about others’ belief. To deal with ethno-culture issues, patients should be allowed to express their wishes. Unresolved cultural dogma can lead to a complex bereavement problem. Bereavement counseling should be offered continuously to identify family members who are at risk for pathological grief following the loss of the loved one.

Some has mistakenly referred good death to mercy killing or euthanasia in which the termination of life is motivated by humane and painless ending of intractable suffering. Cancer and other life limiting conditions can affect patient’s dignity and self worth. Deliberate termination of life, actively or passively, even to achieve good death, is illegal in Malaysia. Key attributes to good death comprises of relief from pain and suffering, awareness of dying, acceptance of process of dying, control, optimism, readiness for departure and choice of where to die. Children’s needs at terminal phase are different depending on age and understanding of the process. Children may require only toys, love, presents and food as part of palliative care. The journey for an individual to experience self satisfaction emotionally, physically, socially and spiritually is referred to comfort care. As a result, if the elements are fulfilled, patients will feel at peace, have a sense of closure and transcendence for the dying individual without much complex grief reactions to the family members.

Conclusion

There is no one single definition of a good death. The aim of palliative care and end of life care is to relieve suffering and
improving the quality of life. Quality end-of-life care is a somewhat dynamic process. The care often is highly individualized. This should be achieved through a process of shared decision making and clear communication that acknowledges the values, self-worth and preferences of patients and their families. A physician requires better communication skills, developmental understanding of trajectory of illness, wealth of individual experiences and understanding of religious and cultural approaches for a holistic palliative care.

References


