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- RIFAT LATIFI: PERSPECTIVE: Swimming Against the Tide and Making It to the Shore: The First Five Years of Kosova College of Surgeons
- BELLAL JOSEPH: The Reemerging Role of Whole Blood in Modern Trauma Care: Is the Whole Greater than the Sum of its Parts?
- RUSSELL J ANDREWS: Efficient Surgery/Neurosurgery: Cutting Costs and Cutting Time Without Cutting Corners
- KRISHNAN GANAPATHY: Quality of Death in Neurosurgical Practice: A 40-year Story from India

# Quality of Death in Neurosurgical Practice: A 40-year Story from India

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## Abstract

Neurosurgeons probably encounter more deaths than most other surgical specialists. The author over a 40-year period of active practice has personally certified over 2500 deaths in Government, Trust and Corporate tertiary care hospitals in a densely populated metropolitan area - Chennai in India. Retrospectively, the author questions whether, in spite of his conservatism and focus on Quality of Life, he should have taken proactive measures to also promote Quality of Death. This perspective reviews literature on Good Death and extrapolates observations and inferences to neurosurgical practice. Changes in approaches to Good Death in the COVID-19 era are also discussed, including its aftermath in the post pandemic era, the influence on lessons learnt across various socio-economic groups, with varied access to technology. This perspective has no research question or specific search strategy. Data extraction, analysis and intervention are also not relevant. The article is an overview of a

current topic of interest, from a neurosurgeon's perspective, highlighting the author's personal experience, and views. The purpose is to share the extensive experience of the author highlighting take home messages from published literature. The author concludes that ensuring Good Death should also fall within the domain of a surgeon's practice. In an era of increasing depersonalization, exponential deployment of technology and social media, this message of ensuring a good Quality of Death is particularly relevant.

**Key words:** Good Death, Good Death AND Neurosurgical Practice, Quality of Death.

## Introduction

Sigmund Freud had once remarked that we are all convinced of our immortality! Discussing death is considered macabre, ghoulish and in morbid taste. The unexpected deaths due to the pandemic have made us review our

traditional “This cannot happen to me” syndrome. Is it time to reconsider the Shakespearean adage “O, let him pass; he hates him That would upon the rack of this tough world stretch him out longer”? Support is relevant not only at the moment of death, but throughout the dying process. When we are closer to death, recognizing our needs – be they medical, emotional or spiritual – becomes more relevant. Earlier understanding is a major part of enabling a good death. Is it desirable to have the option to influence quality of death? Some may wish to hasten the process. Several countries have laws allowing doctor-assisted, active euthanasia. At no point in history have people lived as well as the present generation. So why not focus on the Quality of our Death as well?

Until six decades ago, death was considered a specific point in time - the moment at which life ends.<sup>1</sup> Today, it is accepted that death is an ongoing process – a series of events culminating in irreversible cardiac arrest. A surgeon’s understanding of death, changes as he/she ages. At the peak of one’s career, the emphasis is primarily on preventing mortality, taking every possible measure. Saving lives is the reason for our existence. How often do we ask ourselves, “At what cost?” With time being a major constraint, how often do we spend quality time with the caregivers of an individual whose passing away was highly likely, if not imminent? Do we discuss end of life scenarios? Did we find out the personality of the individual and what he/she would have wanted in this situation? Has the patient made a living will? We are so engrossed in providing intensive critical care, in becoming future-ready, familiarizing ourselves with robotic surgery, Augmented Reality (AR), Virtual Reality (VR), Extended VR (XVR) and protecting ourselves by getting multiple second opinions that we hardly ruminate on the Quality of Death. Some are preoccupied with good Quality of Life and perhaps inadvertently deprive patients of access to “aggressive, heroic “measures.

### Death in Neurosurgical Practice

Gourie Devi in 2014 estimated that in India, 30 million people suffered from major neurological disorders alone, excluding Neurotrauma and infections<sup>2</sup> If one considers acute serious head injuries, neurovascular diseases, malignant brain tumors, degenerative disorders and infections of the nervous system, *daily neurological deaths would be several thousands*. Between 1989 and 2010, neurological deaths for those over 75 outside of the US rose by 117 and 143 percent for males and females respectively. In the USA, the increase was 368% for men and 663% for women. This dramatic rise

was not found for other diseases.<sup>3</sup> A study of deaths associated with neurological conditions in England between 2001 to 2014 showed a steady increase of 39%. 49% of deaths in hospitals and 26% in care homes, involved neurological conditions. 18% of neurological deaths occurred at home, 5% in a hospice and 2% in another place.<sup>4</sup> Neurological disorders account for 16.8 percent of global deaths.<sup>5</sup> Improved life standards, and better health care is postponing death, but often increasing suffering. Neurosurgical practice therefore requires judgment, wisdom and compassion, not just technical mastery of future-ready technology. Management “options” have greatly increased. The problem of therapy is also a problem of choice.<sup>6</sup>

Should not sufficient weightage be given to patient desires, and ethical, social, financial and humanitarian considerations? How much responsibility does the domain expert have in the management of the terminally ill, particularly in an acute or hyperactive acute timeframe? Is end of life care only for chronic disabling conditions? Many neurosurgical conditions like head injuries, hypertensive brain hemorrhage, aneurysmal sub arachnoid hemorrhage occur in “normal” young individuals, where death is not even considered. Neither the clinician nor the family initially discuss End of Life (EoL) management in malignant brain tumors, multiple secondaries and other conditions. Patients with cancer dying in a hospital (36%) or ICU (8%) often receive aggressive care at the end of life, perhaps reducing the probability of a good death. This may lead to bereaved caregivers running an increased risk of developing subsequent psychiatric illness.<sup>7</sup> The surgeon is often oblivious to this. Explaining concept of brain stem death is difficult when the relatives see the monitor displaying a good pulse rate and normal blood pressure. “Grief counselling’ in India could have medico legal issues. At present in most states in India, the patient cannot be taken off life support systems until brain death is declared. Brain death declaration at present is allowed only when consent has been obtained for organ donation.<sup>8</sup> Exposing neurosurgeons to the basics of palliative care may help ensure better EoL management. Understanding psychological, social and spiritual needs at this time is critical, as is developing skills in grief counselling.

### Personal Clinical Illustrations from Neurosurgical Practice

How does one discuss “good death” with a newly married wife, when her husband has had a devastating aneurysmal subarachnoid hemorrhage? How does one inform a retired

Professor of Surgery that he has multiple secondaries not only in the brain but elsewhere and Proton Therapy will at the best only postpone the inevitable? A 92-year-old woman with bilateral hemiplegia is strongly encouraged to be taken home after the diagnosis is confirmed with imaging studies. She also has multiple hip fractures secondary to the trivial fall. Two months elapse. The patient is in a coma for 4 weeks. Morphine patches are being used for analgesia. The 70-year-old son cannot withstand her suffering. After discussion, Ryles tube feeding is also stopped. 72 hours later, she has an irreversible cardiac arrest. The family has been praying for this.

### What is Good Death

The term Good Death was introduced in the 1960s. A Good Death implies that treatment preferences, quality of life and maintenance of dignity have been as per the patient's desires. There has been little or no pain, no distress and suffering for patient, family and caregivers. The death is reasonably consistent with clinical, cultural, and ethical standards.<sup>9</sup> Excessive or futile treatments are not used just to prolong life. There is total trust, support and comfort with the physician and nurse, and the opportunity to frankly discuss all beliefs and fears. The opportunity to say good bye to near and dear is available. When EoL is inevitable and patients or their families' consent, aggressive therapies, medications, and interventions are stopped *but care is never withdrawn*.<sup>10</sup> Death and the process of dying play a central role in all societies and cultures. Ideas are dynamic, fluctuating within groups and during the actual process of dying. Advances in medicine and technology have resulted in longer EoL periods, often making the process of dying more protracted.<sup>11</sup>

Good death is not a single final event, but a series of social events. End-of-life support and care should continually respond in flexible and dynamic ways to the wishes of the dying person. Dying needs to be understood as a process that can be influenced. Though dying is inextricably tied to life, there is a general reluctance to speak about death.<sup>12,13</sup> Having support is important throughout the dying process.<sup>14</sup> Costs also needs to be factored into decision-making. Interventions to improve end-of-life care have important ramifications for dying patients and spouses. Sudden events preclude time to discuss end-of-life issues with family members. According to a Kaiser Family Foundation poll in 2017, 7 in 10 Americans preferred to die at home, an important component of Good Death.<sup>15</sup> Terminal illnesses offer time for discussion and resolution

of "unfinished" psychological and practical business.<sup>16</sup> Good death includes not being a burden to the family, leaving affairs in order and having a sense of fulfilment.<sup>17</sup>

### Concepts of Good Death around the world

There are several studies from various parts of the world, detailing local attitudes on perceptions of Good Death among patients, relatives and healthcare providers. Elderly Japanese regarded "trusting my physician" as the most important component of a good death. In China, good family relationships were considered key requirements. In Shanghai, a good death is perceived as a multidimensional concept, based on sociocultural backgrounds.<sup>18</sup> In India, importance is also given to financial arrangements at the end of life. A report from India suggests that EoL care for quality of life and death is still an unheard topic in most Indian clinical settings. India had several issues in health and well-being, mainly in pain and non-pain symptom management. Only 1-2% of the population in India needing EoL care have access to EoL care or pain management at present.<sup>19</sup> Gafaar et al. reports that there is a general avoidance of the topic in northern Tanzania.<sup>20</sup> What differs amongst cultures is the definition of a 'good death'. With an aging world population, annual deaths are increasing. 80% of annual deaths worldwide occur in low-and-middle countries (LMICs) where there is no tool or protocol to assess an individual's wishes and priorities for EoL care. In Sri Lanka, knowledge and attitudes about EoL care, good death and principles of medical ethics among doctors were suboptimal.<sup>21</sup> Structured training of EoL care needs to be integrated within curricula and in-service training. Quality of dying and death (QODD) in Kenya is worse than in a setting with greater palliative care PC access except in interpersonal and religious/spiritual domains.<sup>22</sup> Cultural differences in perceptions of a good death and the acceptability of death-related discussions may affect QODD ratings. South Korea implemented the "well-dying law" in 2018, enabling patients to refuse futile life-sustaining treatment after being determined as terminally ill. Quality of death in South Korea remains relatively low.<sup>23</sup>

### What is Bad Death

A bad death is one in which there is violence, severe pain, torture, dying alone, being kept alive against one's wishes, loss of dignity, and inability to communicate one's wishes.<sup>24</sup> Most individuals would prefer to die at home, at peace, with family members present. Do we want to be kept alive

at all costs or do we not want to be resuscitated? Knowing our wishes makes it easier for the family and the Health Care Provider. Proper communication makes a difference between good and bad death. During the last few decades, the primary location of death has shifted from home to the hospital— the latter is sometimes perceived as an ominous indicator of a ‘bad’ death. Excessive use of technology, ignoring patient and family wishes, and devaluing quality of life all contribute to a bad death.<sup>25</sup> A death in the Intensive Care Unit is sometimes labelled as a “bad death”, Some perceive ineffective cardiopulmonary resuscitation as contributing to a “bad death”.<sup>26</sup>

### Assisted Dying

Choosing assisted dying is an incredibly difficult decision for all involved. Judging quality of death is very personal.<sup>27</sup> Assisted dying laws allow patients and their families some measure of control over the time and manner of death. Switzerland’s law permitting assisted death has been in force since 1942. In 2014, Belgium extended its 2002 euthanasia law to children. The Netherlands legalized assisted suicide and euthanasia in 2002. In the US, the state of Oregon has permitted self-administered doctor prescribed lethal medications since 1997, under the Death With Dignity Act (DWDA). The state of Washington passed a similar law in 2008, as did Vermont in 2013. Eight states in the USA have passed laws allowing doctor-assisted death.<sup>28</sup> In February 2015, Canada’s Supreme Court ruled that adults suffering extreme, unending pain would have the right to doctor-assisted death. Such legislation has existed for many years. In a landmark judgement delivered on 9th March 2018, a 5-judge bench of the Supreme Court of India recognizing “living wills” made by terminally ill patients, held that the right to die with dignity is a fundamental right. Legalizing passive euthanasia Justice Chandrachud had remarked, “Life and death are inseparable. Every moment our bodies undergo change. Life is not disconnected from death. Dying is a part of the process of living”.<sup>29</sup> On January 19th 2023, realizing that the original safeguards introduced were too cumbersome, the Supreme Court further simplified the rules.

### Death Cafés

Palliative care extends beyond medical treatment of patients. In a number of countries, a movement called Death Cafés offers meetings over tea and cakes where participants can hold open conversations on death, sharing their ideas and concerns with others. At no point in history

have people lived as well as today. Therefore, quality of death is also being discussed. The Death over Dinner movement suggests that groups of friends host dinner parties to process how they feel about death. “How we want to die,” the movement’s website prompts, “represents the most important and costly conversation America isn’t having”.<sup>30</sup>

### Quality of Death Index

India has been ranked 67 out of 80 countries on the 2015 Quality of Death Index, lower than South Africa (34), Brazil (42), Russia (48), Indonesia (53) and Sri Lanka (65) but above China (71). People in the United Kingdom get the best end-of-life care, according to the index; calculated by the Economist Intelligence Unit.<sup>31</sup> Policy interventions and public engagement to improve quality of death through provision of high-quality palliative care have gained impetus in recent years. Recent legislative changes have made it easier for doctors in India to prescribe morphine.<sup>32</sup> Recognising that most individuals are uncomfortable to talk about death, it has been stressed that Quality of Life ‘Dialogues’ need to Include Quality of Death end-of-life care discussions to increase public awareness.<sup>33</sup>

### COVID-19 fatalities epitomizing “bad deaths”

It is now accepted that many primary COVID-19 fatalities were due to neurological complications. Patients with primary neurological conditions leading to death may also get infected with COVID-19. Death associated with COVID-19 is generally associated with “bad deaths”.<sup>34</sup> The death positive movement discusses death whether it is good, bad, ugly or something in-between. Many believe that long term, lasting peace of mind comes from talking about death, voicing one’s concerns and making plans for EoL. Bereavement during the pandemic was devastating for the bereaved kin, whose grief was compounded by their own social isolation and inability to access practical and emotional support. High-stress living situations include financial problems, worries about their own and other family members’ health, and confinement to home. Bereavement during the pandemic has been discussed in great detail.<sup>35</sup> Large gatherings for funerals were restricted worldwide.<sup>36,37</sup> Saying goodbye to a loved one is a ritual that transcends social and cultural differences. Strict social distancing orders forced individuals to find new ways to grieve such as typing comments in the chat section and posting photos online.<sup>38</sup> The fear of dying alone is nearly universal. Hospital policy sometimes precludes

loved ones to be in the ICU at the time of death. This ethical and health care dilemma was compounded in the COVID-19 death. Will virtual video visits be the new normal in a pandemic?<sup>39</sup>

## Conclusion

The last two decades have witnessed an unprecedented deployment of technology in surgery. Textbooks, journals and clinical meetings give guidelines and details of different outcomes with different management plans. Do we factor in the specific desire of the patient? Are we totally transparent during counselling sessions? Unconsciously, inadvertently is our approach influenced, if we are on a “fee for service”? Are we so busy that we cannot commiserate, empathize with the family and the individual who has placed his/her life in our hands? Should healthcare resources be directed to “caring,” rather than “curing,”? When is enough for the terminally ill? Who decides? Should decisions be based only on irrefutable scientific evidence and available technology? Do increased “options” compound the issue? With death as a constant partner do surgeons become insensitive, forgetting that for the aggrieved family death is often the first experience? A consultant “breaking down” is not always a sign of weakness. Permission for organ retrieval was given for South Asia’s first multi organ transplant on Dec 25th 1995, because the author unashamedly broke down.<sup>40</sup> Palliative care normally is outside the scope of neurosurgeons. Discussion of EoL management scenarios often has to be initiated within days or even hours of admission. The situation is more complex, when the moribund patient was in good health before a totally unexpected catastrophe. As surgeons we should at least facilitate a Good Death for those who have placed their trust in us.

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