Responsible Care of the Terminally Sick and the Dying

From Partial Curative Care to Holistic Palliative Care

von J. Charles Davis

It is my joy to write this article for the Festschrift in honour of my doctoral guide Professor Dr. Josef Schuster SJ on his 70th birthday. I chose the topic of *the responsible care of the suffering, the sick and the dying* primarily because Prof Schuster is a kind and virtuous person who has special care for the vulnerable, the suffering and the sick. He is academically rich and resourceful with clarity of thought to discern and decide what is right and what is not. Blended with care and compassion, he always holds that the human being has precedence over norms. It would be appropriate at this juncture to discuss on celebration of life and unconditional care for the vulnerable humans. Secondly, I desire to share my experience as Krankenhausseelsorger at the Uniklinikum Frankfurt, which gave me an opportunity to understand, listen and be with the suffering, the sick and the dying. I listened to their confessions, anointed many with the sacramental oil of the sick and accompanied many patients, and their family members, at the stations of oncology, cardiology, neurology, ICUs and a few patients in the palliative station till their last breath. I witnessed their smiling faces on those last days and departing the world joyfully.

When I look back into the days of my childhood, I remember the practice of appropriate medical care to the dying patients. As I grew up in my village, I saw with my own eyes people dying. Siblings, relatives and friends would be informed of the critical situation of the person. They would regularly visit the dying person. Most of the dying persons spent their last days or weeks or months at home. When there was no medical treatment for an illness, people cheerfully accepted the fact of inevitable death. Family members, relatives and friends would take care of the dying person so well that s/he would not feel the physical and emotional pain. They would make the person comfortable and joyful. They will be with him/her not only in spirit, prayer, but more often physically. Such a solidarity and spiritual care was rendered to the dying person. There was much more trust in prayer and togetherness than in medicine. There used to be a good preparation of the person for death. Though people took medical care seriously, they knew its limits.

People were in very good knowledge of the inevitable death and accepted it gracefully. Not just reason, but intuition might have played a great role in deciding to prolong the hospital treatment or to bring back the patient home at the edge of death. There were no much dilemmas or ambiguous discussions. People could simply sense that he or she was going away from this life. It was time for the person to go, even though it might be painful. This practice continues even now in the villages of India.

Today, with much advancement in medicine and medical technologies, there are plentiful possibilities not only to heal or eradicate diseases quickly but also to prolong or enhance a healthy life. Human beings can be kept alive for longer periods on technological support. Scientists speak of projects of bodily immortality. Those who have economic power would be able to avail such opportunities. Persons in economically less disadvantaged areas may die of an illness, which can be easily cured at another advantaged area. It has become extremely difficult for us to decide whether to prolong the life of a patient in permanent coma. What is ordinary, even basic food, for a patient may be extraordinary for a dying patient. Medical and technological possibilities have challenged our very understanding, meaning and purpose of human life.

1. Two Cases of End of Life Issues and Verdicts of Supreme Court of India

1.1 The Sad Story of Aruna Shanbaug

Aruna Shanbaug was in a coma stage for four decades at King Edward Memorial (KEM) hospital, Mumbai, where she was sexually assaulted by Sohanlal Bhartha on 27 November 1973. Pinki Virani a journalist/activist filed a plea at the Supreme Court of India to end her life to put an end to her endless suffering. However, the Supreme Court of India turned down the plea of Pinki Virani on 7 March 2011, but opened the door for passive euthanasia by laying out guidelines in the absence of any law in India.[1] On 18 May 2015 she had a natural death due to pneumonia.

[1] "India joins select nations in legalising 'passive euthanasia'", in: The Hindu (7 March 2011). The guidelines say, "passive euthanasia involves the withdrawing of treatment or food that would allow the patient to live". Accessed from http://www.thehindu.com/news/national/article1516973.ece (20.01.2016).

1.2 The Jain Santhara Practice of Fast unto Death

The Supreme Court upheld religious freedom for religious practices through its judgement on 1 September 2015 on fast unto death – Santhara or Sallekhana – practice of Jain tradition stating that it was "simply a Jain way of mastering the art of dying as much as the act of living", and stayed the order of Rajasthan High Court which had compared Santhara, the Jain ritual of fasting unto death, with suicide and made it an offence punishable under the Indian Penal Code (IPC).[2] The actual case began a few years back with a plea at the court:

> In 2006, Jaipur-based lawyer Nikhil Soni filed a public interest litigation and sought directions under Article 226 to the central and state governments to treat Santhara, the fast unto death practised by Swetambara Jains (Digambars call it Sallekhana), as illegal and punishable under the laws of the land. Calling it suicide and, therefore, a criminal act, the PIL also sought prosecution of those supporting the practice for abetment to suicide. The PIL argued that death by Santhara was not a fundamental right under Article 25 (freedom of conscience and free profession, practice and propagation of religion), because it violated the right to life guaranteed under Article 21. It argued that religious freedom is subject to public order, morality and health.[3]

These two cases and the verdicts call us to think and reflect deeply on three fundamental questions: (a) What is the fundamental moral value of human beings? (b) Are religious practices above the fundamental human right to life? And (c) what alternatives do we have to take care of the patients when medical treatments become futile?

a) The Fundamental Moral Value of Human Beings

Christianity has always upheld the sacredness of human life. Other religious traditions, like Hinduism, Buddhism and Islam, also believe in the sanctity of human life. Christians believe that all human beings are created in the image and likeness of God (Gen 1: 26–27). Human beings are "children of God" (Jn 1: 12) and "sharers in the divine nature" (2 Pet 1: 14). Humans are images of God and share His sanctity themselves. This inher-

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[2] *M. Ghatwai*, The Jain religion and the right to die by Santhara, in: Indian Express (2 September 2015). See http://indianexpress.com/article/explained/the-jain-religion-and-the-right-to-die-bysanthara/#sthash.kLozw CO0.dpuf. (24.01.2016).
[3] Ibid.

ent sanctity of humans reflects "the inviolability of the Creator Himself"[4], and expresses the inviolable dignity of human life itself. This dignity is present in every human being independent of biological origin, gender, ethnicity, social status, intellectual capacities, external appearance or philosophical worldview or religious convictions.[5] The dignity of life begins right at the time of conception. In all its teachings and doctrines it has emphasized the basic right of everyone to have a decent and dignified life till the last breath. It has shown care and concern even to the last and the least in the society.

Every human life is valuable and important, whether they are in the womb, preborn or unborn, or new-born, healthy or handicapped or vulnerable, rich or poor, young or old or at the deathbed. The belief in the sanctity of life should influence our decisions on euthanasia, suicide and life support. This respect for human life has to be extended to every human being including one's own without discrimination. The most fundamental good in human life is the life itself and body is the prerequisite for human life to exist. Therefore, preserving, promoting and protecting human life existing in a human body is important. However, human life is not absolute. In conflict situations, we may have to take decisions following the ethical parameters. In self-defence, one may have to protect oneself against the aggressor.

The modern world has the tendency to "transform death into an artificial event which is intended to enable the terminally ill, who no longer have any prospect of recovery, to depart silently from the community of the living", and to view that "the presence of the sick, the suffering and the dying is nothing but a burden which the rest of the society wishes to avoid"[6]. The principle of the non-disposability of human life protects life in all its stages

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[4] *John Paul II,* Encyclical Letter "Evangelium vitae" on the value and inviolability of human life (25 March 1995), in: Acta Apostolica Sedis 87 (1995) 401–522, No. 53.

[5] The Catholic Church has equated the image and likeness of God to the foundation of inherent sanctity and dignity of human life, see Congregation for the Doctrine of the Faith, Instruction "Dignitas Personae" on Certain Bioethical Questions, in: Zenit (12 December 2008) and Acta Apostolica Sedis 100 (2008) 858–887, No. 22. "Dignity belongs equally to every single human being, irrespective of his parents' desires, his social condition, educational formation, or level of physical development."

[6] *E. Schockenhoff,* Ethical Guidelines for the Decision on the Discontinuation of Treatment and the Provision of Palliative Care at the End of Life in Intensive Care Medicine, Keynote Address: FIAMC Oration at the Symposium on Preserving, Promoting and Protecting Human Life, Mumbai: St. Pius X College, October 2014, 11–17, 11.

and in all its forms. It applies to the healthy and the sick, the recuperating and the dying. A truly democratic and humane society should uphold the principle of protecting the vulnerable people unconditionally. Dying with dignity makes sense only when protection and solidarity are extended to the dying till the end and not in showing them a way to depart from this life prematurely. Genuine care demands a willingness to show patience and endurance to remain with the patients sharing their wait for death. Schockenhoff says, "Sharing and enduring their powerlessness is a symbol of deeper human solidarity and signals much greater respect for the dignity of the dying person than seeking a way out by intentionally causing death, either by his or her own hand or someone else's."[7]

b) Religious Freedom versus Fundamental Right to Life

The constitutions of many nations permit religious freedom for expression and practices of their life, faith and rituals. However, prior to religions, human beings have an inviolable right to life. Religious practices cannot thus be contrary to the fundamental right to life itself, because religious practices are basically to serve and protect human lives. One may need to judge: whether the Santhara practice equates to a suicide at all? or is it a gradual process of the matured humans who attain their salvation in the near future after having lived their life and fulfilled the duties of their lives well? While the aim of a Jain may be to achieve nirvana (salvation), the gradual outcome could be death itself. What is here willed is nirvana and not death. Death is neither desired not sought, though death becomes the means to nirvana. Where does the thin line lie? Every individual case has to be analysed. In any case, fundamental right to life is not to be tampered with in the name of religious freedom. The right to life does not mean the right to die.

"The embryo as well as the handicapped and patients in the coma state are all persons with dignity and any intervention on their body is to be in accordance with and respecting the dignity of the human person."[8] The embryology affirms that the human person begins right at the time of fertilization, when sperm and ovum merge together: "fertilization marks the beginning of the life of the new individual human being"[9]. Hurlbut says

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[7] Ibid., 12.

[8] *F. Chittuparambil,* The Human Body in Bioethics: Christian and Upanishadic Perspective, Bangalore 2011, 492.

[9] *S. Gilbert,* Developmental Biology, Sunderland ^{5}1997, 60.

that "the act of fertilization is a leap from zero to everything."[10] The new organism is complete from the moment of fertilization and nothing is thereafter added to the existential and moral aspect of the embryo. Life is a gift from God who is the source of life (Ps 36:9). Every human being has the right to life in its totality and no one is allowed to take his/her life or the life of someone else.

c) Withdrawal of Futile Curative Treatments to Palliative Care

"Thanks to good medical care and compassion from others, they [patients] are able to live out their lives in an environment that has personal meaning for them, they no longer express a wish to end their lives prematurely or to be killed. More provision of palliative care units and non-clinical hospices, which ease the transition from the home to inpatient care, is therefore the right way for a human society to care for the dying persons in its midst."[11] Today, there is a need not only of curative treatments but much more of a value judgement while caring for the dying. Appropriate treatment for an acutely ill patient may be inappropriate in the dying. With the end of curative options, the responsibility of the physicians does not end, but the goal of the treatment changes. It is, "no longer focusing on healing but on the control of symptoms and the relief of pain"[12]. Schockenhoff enlightens:

> Any treatment must be reasonable, necessary and proportionate if it is to be medically indicated. If any of these conditions is not fulfilled because it places a disproportionate burden on the patient, the continuation of the treatment is no longer indicated. At that point, it may be not only ethically justified but, indeed, an obligation to withdraw life-sustaining treatment which merely prolongs an agonising death. This applies to the discontinuation of artificial respiration or the withdrawal of artificial nutrition, for example. Every patient has the right not to be prevented from dying by medical interventions which merely cause disproportionate and unreasonable suffering for the dying person him- or herself. The cessation of curative treatment, the discontinuation of artificial respiration or the withdrawal of nutrition do not equate to actively causing death. Similarly, palliative care, whose purpose is to relieve suffering,

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10 *W. B. Hurlbut,* Framing the Future: Embryonic Stem Cells, Ethics and the Emerging Era of Developmental Biology, in: Pediatric Research 59: 4/2 (April 2006) 4R–12R, 8R.

11 *E. Schockenhoff,* Ethical Guidelines (cf. note 6), 12.

12 Ibid.

> does not equate to killing on demand, even if the associated measures may mean that death occurs more quickly.[13]

The criteria for the "*forgoing of treatment* [must] apply equally to the gradual *reduction in the intensity of treatment* or, in situations in which this is impossible, to a *final discontinuation of treatment*"[14]. Schockenhoff is precise and unambiguous, when he states:

> [A]ny form of treatment can be withdrawn or discontinued completely if it cannot achieve its original goal. Medical interventions which are no longer curative in any way but merely serve to temporarily delay, by artificial means, the inevitable moment of death do not fall within the scope of the duty to preserve life. Nor is there a duty to continue treatment which has no prospect of success, which some physicians justified in the past in an effort to avoid blurring the boundaries to active euthanasia. If treatment no longer serves to restore health or, at the very least, maintain the patient's awareness of his/her own existence and ability to communicate with others, if only to a limited extent, its continuation cannot be justified.[15]

2. Palliative Care is Holistic

Palliative care emerged as a medical speciality in 1987. The WHO defined palliative care as '*the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life*'. The verb 'to palliate' means to mitigate, to alleviate, to lessen the severity of (pain or disease), or to give temporary relief."[16] The *Encyclopedia of Applied Ethics* defines, "Palliative Care is the active total care of patients and their families by a multiprofessional team at a time when the patient's disease is no longer responsive to curative treatment and life expectancy is relatively short."[17] The Latin word *pallium,* meaning a cloak or cover, implies that when cause cannot be cured, symptoms are "cloaked" or "covered" with specific treatments.[18] Its basic philosophy is that patients

13 Ibid.
14 Ibid.
15 Ibid.
16 *World Health Organization,* Cancer Pain Relief and Palliative Care in Children, Geneva 1998, 8.
17 *R. Twycross,* Palliative Care, in: R. Chadwick et al. (ed.), Encyclopedia of Applied Ethics, Vol. 3 J–R, London 1998, 419–433, 420.
18 Ibid.

need to be taken care holistically. The goal of the palliative care is to improve quality of life of the patient as well as of the family members. The holistic palliative care approach includes physical, emotional, spiritual, existential and social aspects.[19] It focuses on improving life and providing comfort not only to dying persons but to the people of all ages with serious, chronic, and life-threatening illnesses. It is a support system to help the patients to live as actively and creatively as possible until death, thereby promoting autonomy, personal integrity and self-esteem.[20]

Palliative care ministers include physicians, nurses, social workers, counsellors, psychologists, chaplains, pastoral workers, spiritual counsellors and so on. Each professional contributes to the total welfare of the palliative patients. Physicians and nurses have to overcome the temptation of treating the patients only from the medical perspectives; rather they need to take spiritual and existential dimensions seriously. This holistic palliative care makes the patients comfortable and confident to face the inevitable death. The palliative care ministers can hold on to their own convictions and spiritual values while treating the patients.

It is not possible to offer good palliative care without a proper commitment to openness and honesty. From my experience as the hospital chaplain especially at the intensive care units and palliative stations, I realized how much strength that a chaplain can enthuse in a person at hospital beds. The patients place tremendous amount of trust in the chaplains on those last days. Confidential matters that needed spiritual and mental reconciliation with persons of the family and the society are shared. The palliative stations prepare the patients for a joyful death and a peaceful going from this world. No more regrets, no more ill-feelings, but joyful end brings the family members to accept the end of life easily.

Palliative care both affirms life and accepts dying as a normal process. It is not our duty that we must protect the life of any patient at all costs. It is not possible either, since everyone has to die one day without exception. However, palliative care seeks "neither to hasten nor to postpone death"[21]. While not limited by "tyranny of cure", palliative care is steadfastly opposed

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19 *D. Doyle/D. Barnard,* Palliative Care and Hospice, in: S. G. Post (ed.), Encyclopedia of Bioethics, Vol. 4 N–S, New York [3]2003, 1969–75; *J. Andrew,* What is Palliative Care?, in: Journal of Palliative Medicine 1/1 (2005) 73–81.

20 *R. Twycross,* Palliative Care (cf. note 17), 420.

21 *E. Davies/I. J. Higginson,* The Solid Facts: Palliative Care, Copenhagen 2004, 14–17.

to euthanasia. It respects life even at the point of death. The ethos of care goes beyond the ethos of cure. The ethos of care has human dignity as its central value and stresses the solidarity between the patient and the care-givers with compassion.[22]

3. Palliative Care is Ethically Justified

Palliative care will help reduce the unbearable physical pain while affirming the aspect of human suffering. It helps however to cope with the pain and suffering positively. Can ethics tradition justify palliative care? Is it right to increase the amount of morphine to the patient at the end of life in order to address the pain, and thereby indirectly hastening death because of morphine's effect on the respiratory system? According to the principle of double effect developed by Thomas Aquinas in his work *Summa Theologica,*[23] it is morally permissible to perform an act that has good and bad effects, provided the following conditions are met: (i) the act must not be intrinsically evil, but good or at least indifferent; (ii) the good effect must be the intended outcome and the evil effect the unintended outcome; (iii) the good effect must not be caused by the evil effect; (iv) there must be proportion between the intended good and the unintended evil.

Bridget Campion, a catholic bioethicist, has applied the double effect principle to palliative care and pain relief at the end of life. The intended good of pain relief is within the normal standards of medical practice. Pain relief is not intrinsically evil. The increased dose of morphine has the unintended risk of hastening the patient's death which is possible but not sought. The intended good is not achieved through hastening death of the patient; rather it is only a side effect unlike in the case of physician assisted suicide where the death is the means to put an end to the patient's suffering. There is also a great proportion between the intended good and the unintended evil. By increasing the dose of morphine and thereby relieving the patient's physical pain, the carers make it possible for the patient to attend to outstanding issues, such as, spiritual or family reconciliation, or provide freedom from physical suffering prior to death which is good both for the pa-

[22] *R. Twycross,* Palliative Care (cf. note 17), 420.

[23] New Catholic Encyclopedia, [2]2002, Vol. 4. *F. J. Connel,*"Principle of Double Effect", 880.

tient and the family. The risk of hastening of death might be tolerated in the process.[24]

Palliative care is thus ethically justified and should be lawfully promoted. The Catholic tradition which finds the principle of double effect perfectly valid and justifiable by reason not only accepts the hospice practice of palliative care but will also promote it within its proclamation of God's love for the suffering and the sick.[25] It falls within the manifesto of Jesus who affirmed the life of everyone including sinners and accepted the existential fact of suffering on a cross as a model for human beings.

4. Conclusion

The dual social commitment of the physicians is to preserve life and to relieve suffering. At the end of life, however, relief of pain and suffering becomes of even greater importance as preserving life becomes increasingly impossible. The art of the medicine is to decide when sustaining life is futile, and therefore, when to allow death to occur without further impediments. Physicians are not obliged ethically or legally to preserve life "at all costs". There are many occasions when it is appropriate to "give death a chance". While deciding about the appropriate treatment the physicians have to bear in mind:

- the patient's biological prospects;
- the therapeutic aim and benefits of each treatment;
- the adverse effects of treatment;
- the need not to prescribe a lingering death.[26]

Palliative care attempts to restore the quality of life, the value of life and the meaning of life. At all times, the intrinsic worth and dignity of the patient is maintained.[27] Palliative care treats people with respect and en-

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24 *B. Campion,* Pain Relief at the End of Life: An Application of the Principle of Double Effect, in: Bioethics Matters 13/2 (2015) 1–4; *D. L. Christie,* Last Rites: A Catholic Perspective on End-of-Life Decisions, Lanham 2003, 30–36.

25 Palliative care has a theological foundation in the Sacrament of the anointing. *G. Beuken,* Palliative Care: A Theological Foundation – Sacrament of Anointing and Pastoral Care of the Sick, in: Scottish Journal of Healthcare Chaplaincy 5/1 (2002) 36–40.

26 *R. Twycross,* Palliative Care (cf. note 17), 427.

27 Ibid. See also *N. Dickey,* Withholding or withdrawing life-prolonging medical treatment, in: Journal of the American Medical Association 256 (1986) 471.

sures that they do not feel they are a burden. It promotes human dignity and recognises the patient as a real person rather than their illness.[28] Palliative care exemplifies the parable of Good Samaritan reaffirming the dignity of people in need of responsible care. Death with dignity is not achieved through the relief of physical pain but much more through the relief of emotional pain, for human being is more than the body. While palliative care aims at killing the pain, assisted suicide kills the patient.[29] As Pope John Paul II says, assisted suicide and euthanasia are forms of false mercy (*Evangelium vitae,* 66–67). Palliative care expresses true love for life and true mercy for the patient/person.

When the accuracy of the diagnosis hints that death is imminent or when the curative care is futile even when the death is not imminent, it is not unethical to discontinue all means of life-prolonging medical treatment, which includes medication and artificially or technologically supplied respiration, nutrition, or hydration.

[28] *H. Chochinov,* Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care, in: BMJ 335 (28 July 2007) 184–185.

[29] *R. M. Doerflinger/C. F. Gomez,* Killing the Pain Not the Patient: Palliative Care Vs Assisted Suicide, accessed from http://www.usccb.org/about/pro-life-activities/respect-life-program/killing-the-pain.cfm (18.01.2016).