Euthanasia: A Social Science Perspective

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The social sciences, more specifically medical sociology/ anthropology have extensively probed issues related to the body, illness and pain. However, issues surrounding death and dying, more specifically, euthanasia are relatively conspicuous by their absence. This article seeks to show up the contexts that define euthanasia as a "just" option. It attempts to unravel other issues like the quality of end-of-life care, familial support, degree of dependency, agency in decision-making, ethical dilemma and related discourses that help us understand euthanasia in cross-cultural contexts.

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The social, cultural, and legal acceptability of euthanasia or death with dignity is of late finding greater space for open public discussions in many countries including India.1 The Supreme Court of India's judgment on the Aruna Shanbaug case opens the doors to a consideration of several issues including the right to a dignified death (suggesting decriminalisation of attempts to suicide), distinctions between active and passive euthanasia and more importantly facilitates a wider discussion on the rather sensitive issues of death and dying.2 Even though the term euthanasia is relatively of recent origin, the notion of a good death is an old one which is often culturally constructed. In India, for example, there has always been a cultural acceptance of the idea of self-administered death couched in spiritual practices such as moksha. Such notions of death in the Hindu and Jain scriptures, for instance, relate it to specific notions about the body and purpose of human life.

Swami Prabhananda (2008: 64) notes that in many eastern cultures the "death of a body is not the end of the real entity which is none other than the soul. Man's life on earth provides an opportunity to do moral exercises...". Hockey (1990) in a rare anthropological work on experiences of death demonstrates that conceptions of both death and life are expressed and generated through culturally specific forms and/or institutions. Singh (2008) discusses the culture sensitive end-of-life care of the elderly and terminally ill patients through a specific case study of Kashi Labh Mukti Bhawan, Banaras which houses a large number of such old and ill people. Here, the rituals of dying are facilitated within the religio-cultural matrix of Hinduism that constructs death as a migration from one life to another mediated by the mortal death. The practice of santhara that entails the voluntary giving up of one's life through fasting is considered among the Jain community as the ultimate route to moksha and is taken when one feels that life has served its purpose. While there is hardly any research on this practice, anecdotal evidence shows that it is the old and patients with debilitating illness who opt for santhara.³ Elsewhere, in countries like Iceland, issues of life and death are discussed with reference to the almighty, destiny and natural laws (Einarsdottir 2009). The decision to end life must then be understood in such cultural notions about life and death. However the use of the term euthanasia as a viable medical option to a permanent vegetative state draws its rationale on several other grounds, some of which are discussed here.

Euthanasia as 'Death with Dignity'

Euthanasia can be traced back to the intellectual developments and medical technological innovations in industrially advanced countries in the early 20th century that provided human beings greater control over the processes of life. Such control helped in framing world views in which life and death found new social meanings and interpretations. The human lifespan that increased due to the more powerful and effective ways of managing and preventing diseases did not however guarantee a better quality of life (in whichever way such quality of life is understood). Howarth and Jefferys (1996) argue that the irrelevance of the scientific paradigm in ascribing meaning to human lives has triggered a number of popular responses one of which is to shift the management of dying from professionals to the dying persons themselves to control end-of-life decisions including euthanasia.

Such a shift needs to be located in the neo-liberal ideology that promotes the idea of a rational, active individual/consumer making the right choices and taking responsibility for himself/herself.4 "Patient empowerment", "expert patient", "active patients" are the new catch phrases in healthcare literature. This implies that the patient, far from being a passive and submissive recipient of the doctors' orders, is an empowered and informed person endowed with several rights vis-à-vis the doctors to protect his/her own interests. Chief among these rights is the patient's right to select a line of treatment, refuse treatment altogether or seek active intervention to end life and die with dignity.

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Such perspectives on the rights of the patient to die with dignity and articulate death around positive connotations like "dignified" death, "respectable" and "peaceful" death in a manner which upholds that good death is preferable to a very poor quality of living. The positive notions of good death are contrasted with such concepts of life as "good quality of life", "meaningful, respectable, useful and productive life". Consequently the inert, passive and meaningless vegetative existence characterised by pain, and suffering which puts one at the mercy of others is not considered worth living. The patient and his family members, therefore, have an option to put an end to such an existence and let the person die a dignified and quick death.

The argument for a poor quality of life contrasted with dignified death needs to be read in the context of the declining role of family as a supportive and caring unit to manage the sick. This responsibility of the family in many places has passed on to governmental and private agencies and trained medical personnel. In India, however, there is hardly any organised effort towards end-of-life care and hence patients with debilitating illness are forced to depend on family members with or without willing support. Such a degree of dependency, studies have shown, is closely linked to the desire for euthanasia (Seale and Addington-Hall 1994, 1995a, b; Howarth and Jefferys 1996). Howarth and Jefferys (1996) rightly argue that euthanasia as an end-of-life decision reflects changes as much with professional-patients relationships as inter-general kin relationships. Discourses on death and dying hence need to be situated within the discourses on ageing.

The rationale for euthanasia also draws from a utilitarian logic. The terminally ill and those who are in a vegetative state of existence require more care as they are dependent on others for even the simple tasks of daily life. Such a state of existence has potentially extensive financial implications for the medical establishment, the State as well as the family. The rising cost is an important consideration in the medical management of terminally ill and nonsalvageable patients. It covers not only the monetary expenditure but also the financial

and social opportunities lost, the time, effort, and emotional energy expended by the family on the patient and the diversion of hospital resources and efforts of the care-givers from caring for the curable sick to keeping alive (often artificially) non-salvageable patients in hospital wards.⁵

Unpacking Pertinent Issues

Euthanasia though argued to be a viable option on medical, economic, moral and ethical grounds, nevertheless has always been shrouded by debates and controversies all over the world. The case of Terri Schiavo in the us brings some of these controversies to the surface. This case led to long drawn legal battles over the issue of switching off the life support systems that were keeping alive the unconscious, non-salvageable Terry Schiavo for 14 years (BBC News 2005). This legal battle led the then President George Bush with his "care of life" advocacy to intervene to get the feeding tubes reinserted though briefly. On 18 March 2005 the feeding tubes supplying nutrition and fluids to the body of the 41-year old Terry, were removed. Terry's parents fought to keep her alive by retaining the tube in a feeding position because they saw signs of consciousness in her. Michaels Schiavo, Terry's husband and legal guardian, fought for removal of the tubes so that she could die peacefully and naturally. He contended that his wife would not have wanted to live in this condition and would have opted for euthanasia but Terry had not left any written living will. On 31 March 2005, Terry died a slow death by starvation.

In a contrasting outcome, Aruna Shanbaug in India who has been bedridden in the кем hospital in Mumbai in a permanent vegetative state for the last 38 years after a brutal sexual assault was allowed to live through a landmark Supreme Court judgment in March 2011. The Supreme Court rejected the plea for euthanasia filed by an author-friend of Aruna on the grounds that (a) Aruna's medical conditions do not qualify as "brain dead" and that she breathes on her own, and (b) only the KEM hospital staff who have been the sole caregivers for so long are entitled to plead for euthanasia on her behalf (in the absence of a living will and involvement of any family member). Hence, unlike Terry Schiavo, Aruna Shanbaug has been allowed to live with the help of the emotional and medical nurturing of the hospital staff till her natural death and it is assumed that such a death would qualify for a dignified death.

These episodes give us an opportunity to raise and understand several issues that are at stake on aspects of life, death and dying. Euthanasia, passive or active, raises the key issue of agency – "who does and who should control the decisions to hasten or procure death" (Howarth and Jefferys 1996).

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Both the Terry Schiavo and Aruna Shanbaug cases discussed above highlighted the contentious issue of agency raising questions on who constitutes a "family" of the patient exercising the right to let her live or die. One of the major arguments against euthanasia is precisely that "the philosophy and respectability can be mutilated and used to suit anyone but the subject in question" (Duttagupta 2008: 254).6

In active euthanasia it is important to ask - how much do we know about why patients seek euthanasia? While more research is needed on the social contexts of end-of-life care and decisions, a few studies in the UK do talk about how factors like loss of autonomy, and the degree of dependency along with severity of irreversible suffering have been significantly linked to demands for end of life decisions (Seale and Addington-Hall 1994, 1995a and 1995b; Van den Block et al 2009) and how conversely patients have accepted the natural course of death despite severe physical discomfort in terminal illnesses in situations of strong family and physician support (Duttagupta 2008).

The desire for euthanasia is associated with terminally ill patients but does the patient always know that he/she is a terminal case? Who informs him or her of this? Does every such patient accept this terminal status for him/herself? Zimmermann (2004) in a review of hospice and palliative care literature discusses the discourse on patients' denial of terminal illness and impending death. Patients' denial in this literature has been looked upon in a number of ways – as a conscious or unconscious defence mechanism, which might be healthy and denial as a noncompliant behaviour as it obstructs certain kinds of care. In the latter, such noncompliance is linked to the discourses on dying particularly in western society which invites patients to participate in the planning of death. Anecdotal evidence from other contexts like India shows that patients do not expect to be told about their terminal illness by the "good doctors". Also, issues of life and death (in addition to the doctors) are also assumed to be managed by superior forces leaving room for expectations of a miraculous cure.

Further, is the severely ill patient in an appropriate mental state in which he/she

can evaluate his life situation objectively and rationally as the advocates of euthanasia prefer it to be? Is it indeed possible to make decisions on one's life and death, both of which are emotionally charged issues, without the involvement of one's own and others' sentiments and emotions? Should emotions be of lesser validity as compared to strict medical and economic grounds? Einarsdottir (2009) succinctly brings out the perplexed role of parents as emotional experts in end-of-life decisions of pre-term infants in Iceland. This aspect of emotion brings back the issue of agency - who should take the decisions for termination of life? While medical professionals and bioethicists use emotional involvement as an argument against the rights of parents to be involved in such end-of-life decisions, parents strongly feel that the child belongs to them and they have the right to decide the future of their children (ibid).

Even when euthanasia is understood in the framework of the right of the patient to a dignified death, it is important to understand that rights of persons do not exist in a vacuum, but are exercised within the context of social roles - one's own and those of others, which dovetail into each other. This also means that till the moment of death, a person, even if on his/her death bed, is a social being that carries meaning for others and is vested with social obligations and privileges towards them. A few anthropological literatures thus link the issue of end-of-life decisions and constructions of life and death to the notion of personhood (Kaufman 2000; Einarsdottir 2009; Kaufman and Morgan 2005).

In many cultures, such as India, in which the autonomous individual is slowly emerging, the processes of life and death are carried out in social contexts in which religion, morality, social obligations, mutual support, etc, are the determining factors in any decision-making. The well-being of the larger units of family and kinship might be at stake in the individual's living or dying. Therefore, others may or may not endorse the person's decision to terminate his life, even though he may be in a vegetative state of existence. To take an example, in Hindu society there is a huge difference in the social and ritual status, rights and privileges of a married woman as compared to a widow. Therefore, even if the husband is in a coma, the woman is considered married and not denied the status, privileges and favours extended to married women till the husband's last breath. In such cases, the wife would never easily opt for euthanasia for her husband.

Further, exercising the right to a dignified death could also be problematic in situations of marginality based on ethnicity, class and gender. Duttagupta (2008) by offering two contrasting cases of deaths of women in India and the us respectively raises precisely this issue to ask "how many Indian women know when and where to exercise their rights and dignity"? Considering the gender bias faced by many Indian women in their daily lives, can a right to a dignified death be asserted? Discourses on death with dignity hence need to be situated within processes of living with dignity in everyday contexts.

Conclusion

This article makes an attempt to focus on issues surrounding euthanasia from a social science perspective. While the social sciences and more specifically sociology/ anthropology have contributed extensively on health, illness and suffering, contribution on issues around death is relatively scarce. While euthanasia is being discussed of late more openly in countries including India, it has largely remained a medical and legal issue. This article attempted to situate this in a social and cultural context to ask what kind of questions and issues are at stake. It sought to argue that euthanasia needs to be situated in related discourses on everyday life and living, personhood, constructions of death, rituals and symbolic aspects of dying and ageing in cross-cultural contexts. Euthanasia is deeply embedded in cultural traditions and it is important to study these to be effectively able to contribute to the current debates about legalisation of euthanasia. The discussion establishes that euthanasia even when seen in the framework of a right to dignified death becomes an emotive issue full of contradictions and irreconcilable ideological stances. The hierarchy of human and civil rights, the ranking of social positions occupied by the patient and the significant others in his reference group, the degree of the individual's domination and assertiveness in decision-making on

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important events become contentious issues in giving a uniform practical shape to the concept of euthanasia. The analysis also establishes the need for more social science research to understand issues of life and death including end-of-life decisions like euthanasia.

NOTES

- 1 The recent Supreme Court judgment on Aruna Shanbaug, media reporting of sporadic cases of mercy killing plea including extensive coverage of the recent judgment and the bollywood film Guzaarish indicate this phenomenon.
- 2 See The Times of India, 8, 9 and 28 March 2011 (Bangalore edition) for the reporting of the judgment and debates around it.
 - Passive euthanasia is letting a person die by withholding food and medicines and not undertaking activities to prolong life. Active voluntary euthanasia (AVE) is intentional intervention to end life or to expedite the process of death.
- 3 "The Fast Road to Moksha", *The Times of India* (Bangalore edition), 12 January 2011, p 19.
- 4 For more details on this ideology and its implications on individual responsibility and healthcare,

- Arima Mishra (2010): "Deconstructing Self-care in Biomedical and Public Health Discourses" in Arima Mishra (ed.), Health, Illness and Medicine: Ethnographic Readings (Delhi: Orient Blackswan).
- 5 The role of KEM hospital in Mumbai in taking care of Aruna Shanbaug for 38 years is an exceptional case of healthcare practice in India.
- 6 Similar arguments were put forward in the recent mercy killing plea by the 70-year old Karibasamma from Devenagre, Karnataka. For more details see www.dnaindia.com/bangalore/report_bangalore.

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