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Research Article

Salaam Venky: The Demands of Care and the Dilemma of Consent

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ABSTRACT

Chronic illness derails the life of both the patient and the caregiver. It puts people in situations for which one may never be prepared. It brings up morally challenging situations forcing people to act against ones wishes or forces the law of the land to look ahead of the times, beyond the established norm of the day. This paper is an attempt to understand the struggles of caregivers and patients in the face of a debilitating illness, the demands of caring and the question of consent. The paper analyses the movie *Salaam Venky*, which is about a person with degenerative disease who wishes to donate organs but fails to do so as there is no provision for harvesting vital organs from a living donor. Consent and care are vital aspects of treating chronic illness. One can only imagine the plight of caregivers who have to wage war against the established norms of the society while hope is too distant and the situation is too grim.

KEYWORDS: Chronic illness, consent, right to death with dignity, and organ donation

FULL PAPER

The film, *Salaam Venky*, directed by actor-director Revathy, is adapted from the book *The Last Hurrah* by Shrikant Murthy, which is inspired by the true story of Kolavennu Venkatesh, who was a chess player and who fought the Duchenne muscular dystrophy (DMD) for 18 years. DMD is a rare and serious chronic disease. It is progressive, genetic and life-threatening. It causes skeletal and heart muscle weakness. Historically it was considered as a paediatric disease as the patients never survived to see their 18th birthday, usually due to the inefficient cardio respiratory system (Wasilewska 2).

In the opening scene of the movie, we see Venky being brought to the hospital in a critical condition, hardly breathing. This is his second visit to an emergency ward of the hospital in just two weeks. He was diagnosed with Duchenne muscular dystrophy, a genetic degenerative disorder in his childhood, which has no cure. The doctor who has been treating him for years, informs his mother, Sujatha that, though Venky is brave and has been battling the disease for years now, may not be able to continue the same for long.

With the diagnosis Venkatesh was given a maximum of fourteen years to live, but he survived to be 24 years old. He being aware of his condition which was deteriorating by the day without any hope of cure prepares himself and his mother for the worst possible day; when he may lose the ability to talk. He learns to communicate through the sign language and also teaches it to his mother. Through the years he has been nurturing this desire to donate organs and has been relentlessly seeking his mother's acceptance to do so. The mother, who has struggled year after year just to keep him alive is not in favour of this idea. Through the flashback audiences are informed that Venky's father had refused to support his treatment saying it as a waste of time and money. Sujatha was forced to leave her husband's house to continue his treatment. Since then, she has been living with one purpose; keeping Venky alive.

Contrary to Sujatha's attempts to keep him alive, Venky wishes to end his restricted and painful existence in a meaningful way. He yearns to do something for his mother knowing very well that there is nothing he can do other than trying to win an unwinnable battle and being alive as long as he can as a reward for her relentless efforts and struggles. He believes that organ donation can be a way to make her proud. Donating organs was also an attempt to go on living in any way possible for her sake as he understands how important it is for her. He always felt that he has been a burden to his mother and wanted to leave behind something to cherish even if it meant his early demise. Sujatha on realising the inevitable decline in Venky's situation agrees for organ donation.

With his mother's permission Venky wishes to prepare himself for euthanasia and organ donation but soon they both get to know the reality that his and his mother's consent is not enough, they also need the approval of law and the society. Sujatha now begins her second battle; with the law and the society to fulfill Venky's dream. The very first step towards this; discussion with the doctors, results in denial. Doctors make it clear that they do not have any authority in this aspect even though they understand what it means to them and wish to help them both.

Organ Donation:

Orit Brawer Ben-David in *Organ Donation and Transplantation: Body Organs as an Exchangeable Socio-Cultural Resource* writes that organ transplantation is a sociocultural activity which involves the receiver, donor family and the medical team. These three-groups come together with their own interests. The receiver gains a new lease of life, "the donor family gains social recognition and an illusion of immortality for the departed" and the medical team gets prestige and research funds (xvi). He explains, as society distinguishes between kinds of deaths, it also creates a possibility for a person to be socially alive and live for ever even after being biologically dead. "It is precisely by virtue of this distinction that families become encouraged to donate the organs of their loved ones who are brain dead, thus making possible the act of transplantation" (108). He quotes Lifton, who explains that, the belief in immortality is not a denial of death but an informed knowledge of death, which expresses a need for the continuation of a symbolic relationship that existed before and continues after the death of the individual. Immortality is symbolic since in every cultural framework there is a knowledge of the meaning of death and belief in some sort of continuation of life. (110) In this context medical team with their technical knowledge and skill grant immortality to the donor through transplantation and the "donor continues to exist through his organs, which go on living in other bodies; the verdict of death is postponed for the recipient" (114).

This belief in achieving immortality through organ donation is what motivates Venky to seek euthanasia and to donate organs. But in India only those who are declared brain dead can donate organs. Harvesting organs from some one who is alive, even if they are on brink of death is not allowed and considered immoral and crime. Daljith Singh et al., in "Ethics of Organ Donation in India" tracing the evolution of organ donation mention, "The Act of Transplantation of Human Organs laid down the regulations regarding removal, storage, and transplantation of human organs for purely therapeutic purposes" (1089). This act provided the necessary guidelines "to regulate the removal, storage, and transplantation of human organs for therapeutic purposes and for the prevention of commercial dealings in human organs" (1090). Organ donation depends mainly on Dead Donor Rule for procuring organs. Elysa R Koppelman in "The Dead Donor Rule and the Concept of Death" explains that organ

transplantation strictly follows the dead donor rule so that there can be no harm done to the donor. This rule prohibits donation of vital organs from a living person. It plays a crucial role in keeping the utilitarian goal of increasing the organ supply by providing a distinction between life and death (6).

Brain Death:

The term brain death was first used in the conference of the Medical Royal Colleges of the United Kingdom held on 11th October 1976. It was defined as "permanent functional death of the brainstem" (Pandya 17). Francesco Procaccio and Marina Munari in "Determination of Death by Neurological Criteria (Brain Death)" mentions three essential prerequisites to declare someone as brain dead, they are: unconsciousness, absence of brainstem reflexes, and spontaneous respiration drive (28). In the article they do discuss the criticism found against these neurological criterias of death but insist that, "To date, despite speculative criticisms, (brain) death determination by neurological criteria appears as the most reliable, wise, usable, pragmatic, acceptable, and useful way to ensure death declaration in acute patients with direct or secondary diffuse cerebral damage" (40).

Euthanasia:

Vinod K Sinha et al., trace back the origin of the word euthanasia to the English Philosopher Sir Francis Bacon who coined the phrase euthanasia in the early 17th century. Euthanasia is derived from the Greek word "eu" meaning good and "thanatos" meaning death. Thus, euthanasia means a good or an easy death. Euthanasia is understood as administering a lethal medicine to a patient to relieve them from intolerable and incurable pain, it is considered as an act of mercy to end the suffering. Euthanasia can be either active or passive: "active euthanasia refers to a physician deliberately acting in a way to end a patient's life. Passive euthanasia pertains to withholding or withdrawing treatment necessary to maintain life" (178). They quote the opinion expressed by The Medical Council of India from its ethics committee conference in 2008; "Practicing euthanasia shall constitute unethical conduct. However, on specific occasions, the question of withdrawing supporting devices to sustain cardio-pulmonary function even after brain death shall be decided only by a team of doctors and not merely by the treating physician alone... in accordance with the provision of the Transplantation of Human Organ Act, 1994" (182).

Euthanasia is a crime in India, but in a landmark judgement the Supreme Court allowed passive euthanasia to Aruna Shaunbag, who was in a vegetative condition for 37 years. The two-judge bench laid down stringent guidelines and made it mandatory that the high court should monitor the process. "The guidelines included: (1) voluntary request for assistance in dying on the part of the patient, (2) evidence of a terminal

illness, and (3) documentation by the primary physician of the reason for the request and efforts made to optimize the patient's care" (179).

Despite the strict guidelines opponents fear this will lead to slippery slope. Expressing similar opinion Margaret et al., in "Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in "Vulnerable "Groups" write, "Debate over legalisation of physician-assisted suicide (PAS) or euthanasia often warn of "slippery slope", predicting abuse of people in vulnerable groups" (591). They opine that allowing physicians to participate in assisting suicide would be incompatible with their role as healers. They quote British Medical Association, 2003, which states,

In the BMA's view, legalizing euthanasia or physician-assisted suicide would have profound and detrimental effect on the doctor-patient relationship. It would be unacceptable to put vulnerable people in the position of feeling they had to consider precipitating the end of their lives... The BMA acknowledges that there are some patients for whom palliative care will not meet their needs and wishes, but considers that the risks of significant harm to a large number of people are too great to accommodate the needs of very few. (592) Sinha et al., believe, now that we are prolonging the life with artificial means, end of life issues are becoming a major ethical issue which needs our attention and action (183).

Venky's plea for euthanasia so that he can donate vital organs was rejected by the court stating that the law of the land has no provision for euthanasia irrespective of the condition of a patient and however noble the intentions are. But the judge also assures Venky that he will make sure that the matter will be taken up for debate and consideration in the near future. In India now right to die with dignity is guaranteed by the law. Venky died in December 2004, two days after his request for euthanasia was rejected by the court. His story stirred the debate over euthanasia and later with Aruna Shaubag's case passive euthanasia became legally acceptable in India.

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