

Case discussion on the end of life decision making

[Business](#), [Management](#)



I would like to discuss the case of Aruna Shanbaug which became widely debated in 2011 based on which the Supreme Court of India legalised Passive Euthanasia. It was on the cold dark night of 27th November 1973 that while working as a junior nurse at King Edward Memorial Hospital in Mumbai this young lady whose marriage was just a month away was sexually assaulted and choked using a dog chain in the hospital basement by a ward boy, Sohanlal Walmiki. Following this brutal attack Miss Aruna then 25 years old remained in a vegetative state for 42 long years till her death on 18th May 2015. All along she was cared for by the nurses of the very same hospital. However in 2011 based on a plea filed by journalist Pinki Virani, the Supreme Court of India set up a medical panel to examine her and based on its recommendations issued a set of guidelines legalizing passive euthanasia in India.

Through this case I would like to discuss the ethical issues pertaining to ' a person's right to die with dignity' I would like to draw attention to the journalist who happened to visit this nurse in 2010 who by then was in persistent vegetative state (PVS) for close to 37 long years. The contention of the journalist was that her existence in ' sub-human condition' violated her right to live with dignity under Article 21 of constitution of India. Every human person born has the right to live and would prefer to live life to its fullest possible extent expecting the highest quality of life. If this is the truth, then from where does the right to die stem from. Most often cited reason when campaigning for this right that wilfully exhausts human life is, the lack of its underlying diminished quality. If so, it is but imperative for me to ask

what are the qualitative and quantitative denominators or attributes for judging ' quality of one's life' and who decides for and against it.

Background

A lot of water has flowed under the controversy about a person's right to end his or her life. Right from Plato and Aristotle in the ancient times who in principle condemned the act of suicide were lenient in opinion about self killing ground when it was voluntary or compelled by personal misfortune. In medieval times, Thomas Aquinas a catholic priest and Doctor of the Church disregarded self killing on the belief that only God the creator has right over one's life and that killing oneself could cause more harm to the people around especially the family. In more recent times we have views like those expressed by Peter Singer to considers that a human life is worthy of personhood only if it is capable of performing certain cognitive functions like rational thinking, self awareness and has a desire to live.

Discussion/ Reasoning

Well then, the moral and ethical concerns pertaining to euthanasia or assisted dying, revolves around the core values such as autonomy, sanctity of life, trust, love, human dignity, quality of life, rationality and equity. Of these let me start by discussing about the sanctity of human life which paves way for practice of other inseparable values such as human dignity and autonomy. The term Sanctity refers to the holiness of human life and this concept has its origin from the doctrines of the church and finds its meaning in the holiness of God the creator, as humans are believed to have been

created in the image and likeness of God from whom all life comes. This leaves man with no rights to take his or others life. If one was to apply sanctity of life principle in medicine, I feel it will aim at protection of the bodily life of a human individual. In the realms of society this principle could also hint at equality in society slowly making way for the concept of human dignity.

According to Sulmasy et al. human dignity perceived in three dimensions first being the intrinsic dignity which simply stems from the virtue that one is human. Second is the attributed dignity that refers to the dignity a person gets by virtue of his position or status in society and the third is inflorescent dignity which a person gains by his special qualities or virtues. It was Emmanuel Kant who placed respect for person's dignity at the centre of moral theory. It can be noted that dignity and virtue are related in more than one ways. According to the propagators of virtue ethics, if virtues enhance one's dignity, it is also true that there is virtue in respecting dignity. Now then we need to understand how human dignity can be assessed. There are some attributes that are closely entwined with being dignified, for example certain types of attitude, being well behaved, staying in control or possessing enormous knowledge etc can be the defining characters of a dignified person. Then I am prompted to think when a human being will feel the loss of dignity, what are those attributes or circumstances that can lead to loss of human dignity. The practice of healthcare poses special challenges related to upholding human dignity. For some it could be the inability to control ones behaviour both physical and mental, for others it could be the loss of some organs whereas for some others it could be an irreversible

change in their physical appearance that makes them feel a loss of their dignity or self respect. They may not be ready to accept and live in this state of compromised dignity. This fear of losing respect from others and in other circumstance someone else (parent, spouse, relative or friend) feeling that one has lost that dignity that is attributed to human life could be the most relevant reason for seeking to end life.

Quality of life is like value judgement, which means it can be very subjective. Very difficult to define and measure as there is an observed mismatch between the expected quality and the quality that is experienced by a person with respect to time. Improving the quality of life is often the goal of healthcare which is well reflected in the W. H. O.'s definition of health adopted at the Alma Ata in 1948, which defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. How then can we measure quality of life from health care perspective? Haavi Morreim has proposed an objective tool for deciding quality of life in healthcare taking into consideration some of the inter subjectively observed material facts (such as functional capabilities of body and mind, physiological states etc.). This could be used for assessments related to end of life care. Some believe that this term should not be used to value human life as it is a perfect antonym for intrinsic human dignity. Human life is precious irrespective of its superior or inferior quality.

With this background, I will revisit the case of Miss Aruna Shanbagh and draw attention to how her life took its course. Not much was known about her for initial 37 years after she went into PVS. Visits by family and friends

slowly dwindled over time and it was solely the nurses of that hospital who took care of her. For the 42 long years that she was alive, it was the nurses who fed her, sponged her, cut her nails and looked after her so well that she never developed bedsores. However, in 2009 Pinki Virani a social worker and human rights activist who was moved by the plight of Aruna felt that she had 'actually died' on the very day of the assault, it was on that day that her dreams and hopes of a future were killed along with her brain which left blind, deaf and in a PVS. May I quote Pinki who wrote: 'The 62-year-old reality has been locked away? Always in pain, no palliatives prescribed. No teeth. White cropped hair. A feed-pipe running from her nose to her stomach. Feral sounds from a twisted and brittle skeleton. From which finger nails continue to grow, cut into her palms. Prone to diarrhoea, yet no catheter, she was doomed to a very painful, and very slow, death. She aptly described Aruna Shanbaug as a prisoner of the state, held hostage by the quality of its mercy. Aruna who was confined to the four walls of a room was given good nursing care and was forcefully fed to keep her alive, but in actual sense no medical treatment was administered, she was not evaluated by doctors nor was she taken out of the room into the sunlight and she was in pain. So her question was, do you still consider Aruna to be alive? She filed a PIL in the Supreme Court as the victim 'next friend' seeking permission for Aruna to end her life with dignity by stopping the forced feeding. The SC tuned down the petition of mercy killing for Aruna but legalised Passive euthanasia in India by stating that a next friend, or a legal guardian or the state may be given the power to decide to withdraw life and it is the duty of medical care givers to see that this power is not misused. Now this is a

curious long drawn question, if this lady had lost the right to live or was her life not worth living. Did she have the right to decide about that? Was her autonomy diminished in this context that it required somebody else to decide when and how her life should end. Article 21 of the Indian constitution reads as follows: No person shall be deprived of his life or personal liberty except according to the procedure established by law. This right to life does not just mean breathing but is all inclusive of all those elements that contribute to living with dignity.

In the case of a brain dead person like Aruna at what point in time is it appropriate to withdraw the life support and how do we get to know it is her best interest. Since nowhere there is any indication of Aruna Shanbaug's personal preferences for end of life care, it is but imperative that this decision will rest with the surrogate, in this case the hospital staff who took care of her. They are expected to act in the best interest of the victim (beneficence) and their decision will be medically accepted and honoured.

Well then to conclude mercy killing and the end of life decision making is a morally and ethically taxing exercise, which needs to be dealt using a multipronged approach. One needs to heavily rely on the individual's living will if any, a detailed medical evaluation of the condition without external coercion. It is a fine line between the need to respect human autonomy to uphold one's dignity and at the same time minimise the suffering that compromises the quality of life. End of Life decision making should be based on sound bioethical principles and be backed by upright legislative strategies which could go a long way in relieving human suffering thus facilitating a

dignified exit from the face of the earth rather than dying a little by little every day.