

Original Research Article

Assisted dying and voluntary euthanasia: awareness and perception among health care professionals in a tertiary care centre, South India

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Received: 15 March 2020

Revised: 17 April 2020

Accepted: 20 April 2020

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ABSTRACT

Background: On March 2018, the supreme court of India adjudicated passive euthanasia legal which was termed as obsolete by Indian Council of Medical Research. There are varied opinions because of difference in terminologies used in the country. As per the current Indian legislations, the procedure of voluntary euthanasia and assisted dying is illegal. Hence, this study aims in understanding the awareness and perception towards the same.

Methods: A descriptive cross-sectional study was conducted among all the 369 health care professionals employed in the selected departments of a tertiary care institute during the study period. The questionnaire used was content validated and pre-tested before administering it to the participants. It consisted of five domains (in a five-point Likert scale) and were summarized as proportions.

Results: Most of the doctors (64%) and nurses (59.3%) said that euthanasia is illegal in India. About one fourth of the responders encountered a situation where the patient asked for assisted dying or voluntary euthanasia. A total of 65.3% of the participants agreed that it is helping the patient to die and not killing them.

Conclusions: The study demonstrated that the health care professionals had favourable responses for half of the statements. Re-looking into the verdict by the supreme court of India, standardising the terminologies and advocating for 'advance medical directive' would be welcoming steps in deciding the future of assisted dying/voluntary euthanasia in the country.

Keywords: Assisted dying, Voluntary euthanasia, Perception, Awareness, Passive euthanasia

INTRODUCTION

Euthanasia brings controversies, dilemmas and unending debates in India. The issue rises considerably high in cases where a person is severely impaired as a result of brain damage or persistent vegetative state (PAS), chronic cases like West syndrome, canavan disease, diffuse axonal injury, amyotrophic lateral sclerosis (ALS) and patient with a terminal stage of cancer.

To avoid the difference in the terminologies used for euthanasia, the current study used the following definitions as per international standards.¹

Assisted dying

Prescribing life-ending drugs for terminally ill, mentally competent adults to administer, themselves after they have met strict leg safeguard.

Voluntary euthanasia

A doctor directly administering life-ending drugs to a patient who has given consent.

In India, on March 2011, a remarkable judgement owing to Aruna Ramchandra Shanbaug case from supreme court of India legalised passive euthanasia in the most ambiguous way for patients with brain death or in persistent vegetative state. Assisted dying (AD) and voluntary euthanasia (VE) was made illegal in India vide Indian penal code 302, 304 and 306 (abetment to suicide) quoting the low level of ethical standards to which our society has descended, widespread commercialization and rampant corruption.²

Recently, on 9th March 2018, the supreme court of India (SCI) said that, every human has a right to dignified death and promoted 'living will'. According to this will, a person can make a statement in advance that their life should not be prolonged by putting them in a ventilator or artificial life support system.³ Soon after the judgement, ICMR (Indian Council of Medical Research) said in its recent report that the term 'passive euthanasia' has created a lot of confusion and ambiguity in terms of social acceptability. Hence, it is an obsolete term and needs to be differentiated from euthanasia which is an entirely a separate entity.⁴

The need of the hour is to have clear legislation and regulations. The current study aims to assess the awareness and perception towards AD and VE among health care professionals as these stakeholders are an epitome of moral integrity.

METHODS

Study design

This study was a descriptive cross-sectional study.

Study specific setting

The study was conducted in several departments that deals with terminally ill cases and regional cancer centre of a public funded tertiary care institute in Puducherry. It caters to the people of Puducherry and neighbouring districts, reports with daily OPD of 154 terminally ill patients.

Study participants

A total of 369 participants, of whom 121 were post-graduate doctors and 248 were nurses employed in the institute with minimum of one-year experience, were selected for the study purpose.

Study procedure and data collection

After obtaining approval from the institute's ethics committee, the study was conducted during the months of

September and October 2018. The purpose of the study was explained to the participants beforehand and a written informed consent was obtained prior to their participation. A pre-tested, validated, semi-structured questionnaire was used to collect the data regarding their socio-demography, awareness and perception towards AD and VE. For assessing perception towards AD and VE, a five-point Likert scale (completely agree, agree, undecided, disagree, definitely disagree) was used which was later modified to a three-point Likert scale (agree, undecided, disagree) for analysis.

Data analysis and interpretation

The data was collected using Epi collect 5 version 1.1.4 and was exported as a comma separated values (CSV) file and imported in statistical package for social sciences (SPSS) software version 19.0. Continuous variables were summarized as mean (standard deviation) or median (inter-quartile range) depending on the normality of data. Categorical variables were summarized as proportions.

Ethical approval

The proposal to conduct the study was approved by the Institutional Ethics Committee (approval number: JIP/IEC/2018/221), Jawaharlal Postgraduate Medical Education and Research, Puducherry.

RESULTS

Around 61% of the participants belonged to the age group of 26-35 years. Majority (82.1%) of them were married and followed Hinduism as religion (72.6%). More than half of the participants (67.2%) were staff nurse and 41.7% of them had professional experience of six to fifteen years (Table 1).

Among the study participants, 26.3% and 24.1% have encountered a situation where the patient and the family members respectively, had asked for euthanasia. 94% of the participants have never attended any conference or a scientific meeting on the subjects of either euthanasia or MAD (medical assistance in dying) or EOLC (end of life care) (Table 2).

About 16% and 38.3% of the doctors and nurses respectively, answered correctly for the definition of AD. About 82% of the doctors and more than half (55.6%) of nurses correctly knew the definition of passive euthanasia as per supreme court of India. The doctors had a higher level of awareness towards the procedure to be followed for passive euthanasia and regarding advanced medical directive (AMD) as compared to the staff nurses (Table 3).

Under the domain of 'perception towards the application of AD/VE', majority of the respondents (74.3%), agreed that the patient with a terminal illness should not be hopelessly suffering.

About 65.3% of the participants agreed to the statement that it is helping the patient to die and not killing them.

Nearly half (46.3%) of the participants responded that CPR (cardio pulmonary resuscitation) is not a convenient method during the terminal period. Also, 19% of health care professionals agreed that elderly people (>75 years) should be allowed to die who feels their life is complete. Another major finding was that around 39% of them were undecided about the routes of administration to practice

euthanasia. Around 46% of the participants wanted euthanasia for themselves, if legalized.

Major proportion of the participants (61.5%), believed that the decision regarding termination of life should come from the patient's side. Under the domain of 'family participation in decision making', 70.2% said family decision should be considered when the patient cannot decide for himself/herself.

Table 1: Distribution of the study participants by socio-demographic characteristics (n=369).

Variable	Category	Number (N)	Percentage (%)
Age group (in years)	<25	6	1.8
	26-35	207	61.2
	36-45	90	26.6
	>45	35	10.4
Gender	Male	144	39
	Female	225	61
Occupation	Faculty (doctor)	46	12.5
	Senior resident	75	20.3
	Staff nurse	248	67.2
Religion	Hindu	268	72.6
	Muslim	22	6.0
	Sikh	5	1.4
	Christian	69	18.7
	Others	5	1.4
Marital status	Single	62	16.8
	Married	303	82.1
	Divorced/ separated/ widowed	4	1.1
Years of professional experience (in years)	Less than 5	133	36.0
	6-15	154	41.7
	16-25	61	16.5
	More than 25	21	5.7

Table 2: Clinical vignette among doctors and nurses in a tertiary care institute (n=369).

S. no.	Statement (s)	Yes	
		Number (N)	Percentage (%)
1.	Experienced a request of AD/VE from patient	97	26.3
2.	Experienced a request of AD/VE from the family member	89	24.1
3.	Participated in a scientific meeting regarding AD/VE	22	6.0

Table 3: Awareness towards AD and VE among doctors (n=121) and nurses (n=248) in a tertiary care hospital, South India (n=369).

Variable	Statement	Correct		Incorrect		Don't know	
		Doctors	Nurses	Doctors	Nurses	Doctors	Nurses
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Definition of AD	AD is where doctor directly administers life ending drugs to patients who have given consent*	19 (15.7)	95 (38.3)	75 (62.0)	91 (36.7)	27 (22.3)	62 (25.0)
Definition of passive euthanasia	Passive Euthanasia as per Supreme Court of India is the withdrawal of medical treatment with the deliberate intention to hasten a terminally ill-patient's death	99 (81.8)	138 (55.6)	7 (5.8)	34 (13.7)	15 (12.4)	76 (30.6)

Continued.

Variable	Statement	Correct		Incorrect		Don't know	
		Doctors	Nurses	Doctors	Nurses	Doctors	Nurses
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Procedures followed for passive euthanasia	The attending medical practitioner should obtain the opinion of three medical experts whose names are on the approved panel and thereafter he shall inform the patient (if conscious) and other close relatives.	70 (57.9)	118 (47.6)	6 (5.0)	25 (10.1)	45 (37.2)	105 (42.3)
	The attending medical practitioner can withhold or withdraw medical treatment including discontinuance of life supporting systems immediately. *	51 (41.1)	83 (33.5)	29 (24.0)	79 (31.9)	41 (33.9)	86 (34.7)
	It is mandatory to seek a declaratory relief that the proposed act or omission by the medical practitioner /hospital in respect of withholding medical treatments is lawful or unlawful.	52 (43.0)	82 (33.1)	7 (5.8)	26 (10.5)	62 (51.2)	140 (56.5)
	It is the Physician who will give a final declaration*	32 (26.4)	56 (22.6)	28 (23.1)	97 (39.1)	61 (50.4)	95 (38.3)
Advance medical directive	It is a medical power of attorney	41 (33.9)	94 (37.9)	23 (19.0)	44 (17.7)	57 (47.1)	110 (44.1)
	It is a document in which a person states his/ her desire to have or not to have extraordinary life-prolonging measures when recovery is not possible	69 (57.0)	128 (51.6)	4 (3.3)	25 (10.1)	48 (39.7)	95 (38.3)
	It is to be given only by a person who is terminally ill*	41 (33.9)	57 (23.0)	32 (26.4)	112 (45.0)	48 (39.7)	79 (31.9)

*Incorrect statements.

Table 4: Perception towards AD and VE among health care professionals in a tertiary care hospital, South India (n=369).

Domain	Item	Agree N (%)	Undecided N (%)	Disagree N (%)
Application towards AD/VE	Patients without hope should not suffer	273 (74.0)	39 (10.7)	57 (15.4)
	Patients with a terminal illness should not be hopelessly suffering	274 (74.3)	45 (12.2)	50 (13.6)
	Patients with a terminal illness should be allowed to die	143 (32.5)	106 (28.7)	120 (38.8)
	AD/VE is not killing a person, it is helping him to die	241 (65.3)	76 (20.6)	52 (14.1)
	AD/VE should be legalized in all countries	142 (38.5)	116 (31.4)	111 (30.1)
	AD/VE should be considered in a patient who is incapable of giving this decision himself	125 (33.9)	102 (27.6)	142 (38.5)
	AD/VE can be considered for elders aged above 75 years who feels their life is complete	170 (19.0)	68 (18.4)	231 (62.6)
	The life of a person who is in a persistent vegetative state should be ended	155 (42.0)	103 (27.9)	111 (30.1)
	CPR application is not convenient during the terminal period	171 (46.3)	68 (18.4)	130 (35.2)
	Application of AD/VE lessens people's confidence in medicine	155 (42.0)	96 (26.0)	118 (32.0)
	Injecting a lethal drug by a physician is better than prescribing a drug (e.g. Secobarbital) to a person qualifying for AD/VE in giving painless fast death	123 (33.3)	143 (38.8)	103 (27.9)

Continued.

Domain	Item	Agree N (%)	Undecided N (%)	Disagree N (%)
Right to terminate life	AD/VE should be considered for destitute/ mentally handicapped/ without family members having terminal ill conditions	127 (34.4)	87 (23.6)	155 (42.0)
	If legalized, I might want AD/VE	170 (46.1)	106 (28.7)	93 (25.2)
	I am in favour of AD and VE among patients who are terminally ill and shows no sign of recovery	213 (57.7)	71 (19.2)	85 (23.0)
	The AD/VE decision should be taken by the patient who is capable of giving consent	227 (61.5)	57 (15.4)	85 (23.0)
Family participation	Families should always be consulted regarding AD/VE decisions taken by patients	283 (76.7)	46 (12.5)	40 (10.8)
	Families should always be consulted regarding AD/VE if the patient cannot decide for himself	259 (70.2)	60 (16.3)	50 (13.6)
	An unconscious patient's life should be ended with the approval of his family who is not in the state to give consent	167 (45.3)	89 (24.9)	113 (30.6)
Social cost	It is a burden for relatives to take care of a patient with a terminal illness and is expected to die soon	119 (32.2)	92 (24.9)	158 (42.8)
	It is a burden for health organizations in a government set up to take care of a patient with the terminal illness and is expected to die soon	106 (28.7)	71 (19.2)	192 (52.0)
	It is a burden for medical staff to take care of a patient with a terminal illness and is expected to die soon	90 (24.4)	64 (17.3)	215 (58.3)
Right to live with dignity	A person should decide his own right to live	275 (74.5)	45 (12.2)	49 (13.3)
	Advance medical directives are a step towards Right to die with dignity	228 (61.8)	87 (23.6)	54 (14.6)
Influence of religion	AD/VE decisions are affected by religious beliefs	226 (61.2)	69 (18.7)	74 (20.1)

The domain 'social cost' showed that 42.8%, 52% and 58.3% of health care professionals disagreed that, 'It is a burden for a relative, health care organization and medical staff respectively to take care of patient who is expected to die soon'.

Under the domain 'the right to live with dignity', 74.5% of the respondents said that the person should decide his own right to live and 61.8% agreed that advanced medical directives is the step towards right to die with dignity. Around 61% of health care professionals agreed that religious belief affects the decision towards AD and VE (Table 4).

DISCUSSION

The current study suggests mixed responses towards application of AD and VE. Since the study population among the existing studies was heterogeneous, the methodological comparison was difficult. Also, this study might differ in interpretation of results as the definitions of euthanasia used nationally or internationally and their forms show variations hitherto.

Although AD and VE is illegal in India, it was found that health care professionals have encountered situations where 26.3% of the patients and 24.1% of the family

member of the patient have made an explicit request. This was similar to a study conducted in South India by Subba et al.⁵ Also, another study in Belgium revealed that more than half (53%) of the patients had requested for euthanasia to the psychiatric nurses.⁶ This could be perhaps due to the fact that the country where the study was conducted does legalise some form of euthanasia and hence the patient may be outspoken about their request which is hard to see in our country.

Only a small proportion (6%) of the health care professionals had attended any scientific meeting regarding the end of life care or euthanasia. Similarly, a study in Turkey by Kaptan et al, reported that only 8.5% of health professionals had attended any meeting about euthanasia.⁷ This indicates that there is little or no interest showed in the subject of euthanasia which is an integral part of palliative care. In context to advanced medical directive (AMD), previously a study conducted in India reported that 60% of the doctors and 59% of the nurses had a view that 'there should be some legal avenue where the patient can pre-authorize his/her death'.⁸ However, in the present study, there was lack of awareness among the health professionals about AMD.

Out of the twenty four (24) questions, the health care professionals gave favourable responses for half of the questions whereas Kamath et al, reported that 69.3% of

health professionals were in favour of euthanasia as a means to relieve unbearable chronic pain.⁹ Other studies also favoured euthanasia with a 60:40 ratio.^{5,10} However, on the contrary, one of the study did not support euthanasia and considered it as unethical since we are emotional and care driven society and probably it is still considered a taboo to discuss death and end of life.⁸ Also, the fear of its misuse is high due to ‘rampant corruption and mass commercialization’ as quoted by supreme court of India. Majority (65.3%) of the participants perceived that AD and VE is helping a person with a terminal illness to die. Similar results were reported in a study conducted in Belgium among nurses in paediatric intensive care unit where 74% of the nurses said that ‘it is not ethically wrong to hasten the death of the child by administering drugs’ and ‘should not suffer hopelessly’.¹¹

In the current study, 42% of the respondents said that the patient with persistent vegetative state should be allowed to die similar to a study where majority (82%) of the oncologists were against in keeping a brain-dead patient alive.⁸ Around 63% of the respondents did not favour for the statement that the elderly people above 75 years of age who thought their life was complete, can be considered for AD/VE as it challenges our morals and values. More importantly, the issue regarding the mode of administering euthanasia is still unanswered as many of respondents gave a neutral response (38.8%). Injecting a drug and deliberately ending a life is still considered as unethical parallel to present findings.^{12,13} Overall there is more reluctance among Nurses as they spend more time with the patients and relatives. They are experienced to provide quality care rather than killing them. Also, their profession will never allow them to practice and administer euthanasia drugs.^{6,14,15}

However, an international study conducted among nurses, favoured for AD which is in contrast to the current study findings. This probably can be attributed to the difference in ethnic, cultural and religious makeup.¹² In this study, more than half (57%) of the respondents favoured for AD/VE for terminally ill patients who show no sign of recovery. A study by Abbas et al, reported that majority of the participants supported euthanasia in exclusive conditions such as motor neuron disease and terminal cancers.¹⁶

Math and Chaturvedi said, ‘doctors do suggest to the family members to have the patient discharged from the hospital and wait for death to come if the family or patient so desires’, but in the present study, 32.2% of the participants felt that it is a burden for the family to take care of the patient with a terminal illness which was similar to other study findings.^{7,17,18}

This can be attributed to reasons such as poverty and non-availability of the resources. It was a mandate from the present and other studies that patient’s autonomy should be respected with respect to their right to live. About 62%

of the professionals said that the AMD (advance medical directives) is a step towards the right to die with dignity. An increase in knowledge about AMD has demonstrated that patients do not wish for artificially prolonging of life which lessens the financial burden.¹⁹

Majority of responders (61.2%) agreed that religion plays an important role in deciding for AD and VE which is similar to the findings reported in other studies.⁵ In India, deliberate intention to kill a patient is equivalent to murder. Most of the religion doesn’t allow euthanasia or mercy killing, for example, Hinduism believes in the concept of ‘Prarabdha karma’. Also, in a meta-analysis by Charlotte et al, it was reported that stronger the religious faith, higher the chances of opposing euthanasia and its legalization.²⁰

CONCLUSION

Although the current legislation does legalize passive euthanasia yet the image of the term ‘euthanasia’ is creating a misconception among majority of the stakeholders. Nonetheless, standardizing the terminologies, relook into the verdict by the supreme court of India and garnering opinions from health care professionals would be worthwhile. Framing protocols and stringent guidelines for advanced medical directive would aid to combat with the ‘slippery slope’.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Kothari A, Premarajan KC, Adinarayanan S. Assisted dying and voluntary euthanasia: awareness and perception among health care professionals in a tertiary care centre, South India. *Int J Community Med Public Health* 2020;7:2280-6.