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A SURVEY TO UNDERSTAND THE PEOPLE'S PERSPECTIVES ON EUTHANASIA AND PALLIATIVE CARE

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Abstract

In the wake of the aggressive arguments to legalize euthanasia and physician assisted suicide and withholding and withdrawal of treatment it is necessary to understand the general views of the public about the entire killing and allowing to die movement.

There was a survey undertaken to understand the people's idea on the dying process, holding discussions, building awareness and most importantly, trying to analyze the perspectives about an ideal death for a family member or oneself. The intention of carrying out the survey was to understand the attitude of the choices one may think effective when making an end of life decision.

Keywords: *Euthanasia, pain management, physicians, decisions, patients, palliative care*

1. Introduction

Understanding death by way of its definition is "the complete and permanent cessation of all vital functions in a living creature, the end of life" (Callahan, 1994). However, there are colossal ethical, legislative and medical arguments that have been the touchstone of many judicial rulings to either permit or prohibit the end of life decisions for those suffering with a terminal disease.

Patient's, their families and medical practitioners find it beyond human comprehension whether to allow one to end their life or allow them to continue to suffer and writhe in pain. Some families are not even aware of the availability of end of life care treatments and the legalities involved in decision making. This survey was carried out to understand the knowledge of the common public, patients, their families and medical personal thought of dying, assisting to die and if palliative care is provided will patients rethink their request to end their life.

2. Background

What are some of the social, legal, ethical and philosophical implications of euthanasia physician assisted suicide (EPAS) and withholding and withdrawal of treatment (WWT)? In many countries it is still considered illegal to assist a patient in dying even if they beg to kill them so as to end their suffering (Singer, 1999). With India making withdrawal and withholding of medical treatment legal, on March 9, 2018, as the Indian Supreme court gave out a ruling that 'allows passive euthanasia'. "Article 21 of the IPC mentions the final word to determine the law on the subject, of right to life and liberty is given to legislature" (Bachal, 1964). This ruling also made the living will or the advance directive available to an Indian citizen. The big question now, *How and Who can execute a Living Will*? (The Times of India, 2018). There are certain rules that apply while writing out a living will.

- Only an adult of sound and healthy mind.
- Must be voluntarily written, without coercion or compulsion.
- Must be in writing, stating when treatment may be withdrawn or no specific treatment shall be given that can delay death.
- Their will can be revoked at any time.
- The name of the guardian or 'close relative' must be mentioned to give the signal for passive euthanasia.
- The will should be signed by two witnesses and preferably counter-signed by a first-class magistrate. He should preserve a hard copy and send a copy to the district court registry.
- A local custodian will be nominated for the living will, by a local government officer.
- However, under the pre-set guidelines by the judicial body, the court holds that the right to life does not include the right to die.

"The Delhi District and Sessions Judge (Headquarters) Talwant Singh, stated that the Chief Metropolitan Magistrate (Central), has been designated to counter-sign the advance directives of the 'living will'," (Jain, 2018). (Document signed by District and Sessions Judge at the end of the chapter.).

These are some of the issues that all medical, legislative, ethical, psychological, patient's and their family members are trying to come up with some conclusive solution. "The percepts that surround any dying decisions are challenging", (Uhlmann, 1990).

Reaffirming the intrinsic value of a human being is becoming more abstract in nature, believing, it only lies within the realms of philosophical discussions. The fear of legalizing euthanasia and physician assisted suicide – that it will be misused – is part of the exploration. The other concern, of not providing dignity in assisting to die to the terminally ill patients who go through intolerable suffering are left to linger and writhe in pain, some takes drastic steps on their own by committing suicide (Queensland Parliament, 2020). The dangers of voluntary euthanasia gradually turning into involuntary euthanasia will not remain only as a discussion but will eventually change into a reality if permission becomes aggressive.

Arguments on allowing or prohibiting *EPAS* and WWT, were subjected to controversy from the onset of any discussion about the action. Every time a patient or family requests for terminating their life it becomes a debatable subject as people are unable to conclude whether it is right to allow a patient to continue to suffer or wrong to kill a person. Ending a life is a much broader spectrum than just switching off a button or administering a lethal dose to a patient.

One is hardly at liberty to choose to continue to live when they know they are eating into the resources of their family members or and treatment is futile. The idea that they are a burden brings about the desire to end their lives.

Patients should at least be given the option of Palliative Care as it encompasses care as a holistic feature wherein it works relentlessly by providing medical therapies for the well-being of the patient: treating the disease, assisting in increasing the physical strength and abilities and providing counselling for the patient and family i.e. caregiver as well (Khosla & Sharma, 2012). Interestingly palliative care does not shun away the fact of death but tries to resolve the feeling of the dying process for the patient and within the family. Palliative care tries to break the hurdle of communication that lurks in the minds of the patient. It is important that the patient is offered the best opportunity to express their concerns and to be listened to (Faull & Kerry, 2015). Compassion and sensitivity to the feelings of a patient are the key attributes shown by a palliative team. It is in this compassion that patients might change their mind to end their lives.

2.1 Statement of problem

The key question that requires thorough and detailed investigation is: “If adequate care is provided to those suffering intensely, will they still want to end their lives by requesting for euthanasia?”

2.2 Objective of the study

This study aims to seek answers to the questions; the patients, who request to end their life, will they change their mind if palliative care is available? Will palliative care be an option enough to deal with their suffering and to combat the fear of patients who are nearing death?

2.3 Research Methodology

The survey was an intentional mix of a quantitative and interview type discussion. The target was a total of 200 prospective participants that consisted of 4 groups of 50 people. 210 people participated in the survey, out of which 120 were females and 90 males.

The first group was of the general public between 30 to 60 years of age. The second was participants above the age of 60 years. The third consisted of patients, caregivers and family members of terminally ill patients. The fourth group was of medical and palliative care personals.

The questionnaire was of 4 pages, the first page was the introduction and general information about the survey. Part I and Part III were Closed-Ended-Questions, Part II was Multiple-Choice-Question (MCQ), at the end of the survey space was provided for participants suggestions/comments if any.

3. Survey responses

Q.I. On Euthanasia:

Table I (a): Morality of Euthanasia

Do you think euthanasia is morally permissible?		
Responses	**No. of Responses**	**Percentage**
No	101	48.33%
Yes	108	51.67%
(blank)		0.00%
Grand Total	**209**	**100.00%**

Of the 210 respondents, 209 agreed to answer this question. 1 person did not respond since the individual felt that it was an invalid question for a practical situation of life and death. 108 (51.67%) persons felt it was morally permissible, 101 (48.33%) felt it not moral.

Table I (b): Should one be allowed to die for mercy?

Do you think it is right to allow a terminally ill patient to die, for the sake of being merciful?		
Responses	**No. Of Responses**	**Percentage**
No	90	43.27%
Yes	118	56.73%
(blank)	0	0.00%
Grand Total	**209**	**100.00%**

Response to being merciful, 2 respondents did not answer the question. 118 (56.73%) persons answered from the perspective of not allowing the patient to suffer intolerable pain, the other 90 (43.27%) persons felt it is not a strong reason to terminate a patient's life.

Table I (c): Should euthanizing become legal for a physician?

Do you think euthanasia should be legalized for a physician to administer a lethal dosage to end the patient's life?		
Responses	**No. Of Responses**	**Percentage**
No	116	55.50%
Yes	93	44.50%
(blank)	0	0.00%
Grand Total	**209**	**100.00%**

Respondents unanimously felt that if at all euthanasia became legal, physicians will need to follow strict guidelines, so that it does not become an easily accessible measure to evade pain and suffering and embrace death. 116 (55.50%) patients responded that they would not want physicians to be able to euthanasia, 93 people (44.50%) felt that it was a safe measure for physicians to carry out the job as they were professionally knowledgeable and equipped. One respondent couldn't decide as that would be giving too much power to physicians.

Table I (d): Should family members be given power for a mentally/physically incompetent patient?

Do you think a family member should be given the power to decide on the medical proceedings in a situation where the patient cannot decide for oneself?		
Responses	**No. Of Responses**	**Percentage**
No	73	35.27%
Yes	134	64.73%
(blank)	0	0.00%
Grand Total	**207**	**100.00%**

This question had varied perspectives, respondents took longer to answer this question since they had actually placed themselves in a state they may reach in the future and were pondering over the question with great thought. Some persons felt that in case they are too elderly and fragile, they might become vulnerable and a burden to their family wherein the family may misuse this power vested on them. Others felt putting the onus of making life and death decisions might make family members feel depressed and guilty as well. Some felt that they may decide differently for someone else however, they might not want that same decision to be made for them. 134 (64.73%) respondents felt family should be given the power to decide what ought to be done in unforeseen circumstances while 73 (35.27%) respondents were against. Three persons couldn't tell.

Table I (e): Should extraordinary measures be used to keep patient alive?

When a patient is critically ill, do you think extraordinary measures should be taken to keep the patient alive?		
Responses	**No. Of Responses**	**Percentage**
No	70	33.82%
Yes	137	66.18%
(blank)	0	0.00%
Grand Total	**207**	**100.00%**

Respondents felt that extraordinary measures for treatment to a greater extent depends on the economic status of a patient because if a patient has the funds they would not mind going to greater lengths for treatments. Problems arise when the treatment is out of the economic reach of a patient, most often than not this will be the deciding factor of extended, extraordinary or curative treatment. 137 participants (66.18%) agreed with these measures. 70 (33.82 %) persons felt it should not be done. 3 respondents were not sure what to answer.

Table I (f): Should a patient be taken off life support if patient is in brain-dead state?

If a patient is in a brain-dead state and is on life support, do you think the patient should be taken off life support only because they cannot decide for themselves?		
Responses	**No. Of Responses**	**Percentage**
No	95	45.89%
Yes	112	54.11%
(blank)	0	0.00%
Grand Total	**207**	**100.00%**

The question of brain death was met with a lot of criticism. The discussions were intense as some respondents believed that it was not moral for someone else to decide the death

of another. Some even said that people should stop acting as God. While others felt that it was an unnecessary burden on the family for a patient that was brain dead. Some believed that the age of a patient may be the deciding factor of medical proceedings. If the patient is young they might want to continue with medical support. 112 respondents (54.11%) remarked that the patient should be taken off life support. 95 respondents (45.89) said that they will not agree. 3 respondents said that they will not be able to decide on the proceedings of medical interventions.

Table I (g): Should a patient be allowed to die due to intolerable pain?

Will you agree to allow a patient to die only because they are going through intolerable suffering?		
Responses	**No. Of Responses**	**Percentage**
No	127	61.35%
Yes	80	38.65%
(blank)	0	0.00%
Grand Total	**207**	**100.00%**

Surprisingly many respondents felt intolerable suffering was not a good enough reason to allow a patient to die. 80 (38.65%) persons felt that it was a valid reason, 127 (61.35%) persons felt that pain was not enough a reason for ending life. 3 respondents said that they could not answer such a question.

Table I (h): Should resources be spent on treatment even if end is futile?

Do you think it is right to spend resources on a patient even if the end might be futile?		
Responses	**No. Of Responses**	**Percentage**
No	96	47.06%
Yes	108	52.94%
(blank)	0	0.00%
Grand Total	**204**	**100.00%**

A common thought of some whether the end of treatment is futile or not, was not a very strong reason not to spend resources. 108 (52.94%) were of the opinion that it what they would, 96 (47.06%) felt that the resources should not be wasted on a patient if death is sure. Some also believed that it might be more painful keeping a patient alive. 6 people said age, money and the relation with the person would be a deciding factor for future treatment.

Who would tell, but the world is facing the same difficult times with the outbreak of the current pandemic of COVID-19 right now, where to utilize the resources in the most optimum manner is a grave concern.

Table I (i): Will distress to the family be a reason for a patient to lose desire to live?

Do you think if a patient realizes that they are causing immense distress to their family, they will want to continue to live?		
Responses	**No. Of Responses**	**Percentage**
No	112	56.57%
Yes	86	43.43%
(blank)	0	0.00%
Grand Total	**198**	**100.00%**

Many respondents felt that distress was not such a serious reason wherein a patient would want to end their life due to it. Some felt that if patients were highly sensitive and realized the emotional burden they are causing to the family it will, in turn, make them very depressed, this could be a reason a patient may want to die. 86 people (43.43%) agreed to this, 112 participants (56.57%) did not feel it a valid reason. 12 people said that they would not be able to decide on what to answer.

Table I (j): Will patient lose trust in their doctor if *PAS* became legal?

Do you feel that if Physician-assisted suicide became legal in our country, patients would have less faith in their physicians?		
Responses	**No. Of Responses**	**Percentage**
No	85	41.26%
Yes	121	58.74%
(blank)	0	0.00%
Grand Total	**206**	**100.00%**

121 (58.74%) respondents believed that if physicians were given the power to terminate a life, the faith in their physicians would be compromised, 85 (41.26%) persons said that legalizing *PAS* would not affect the trust in doctors. 14 people said that they are not sure of the outcome if *PAS* is legalized.

Table I (k): Will legalizing euthanasia devalue life?

Do you think legalizing euthanasia will devalue all that humanity stands for; every human being has intrinsic value?		
Responses	**No. Of Responses**	**Percentage**
No	93	44.71%
Yes	115	55.29%
(blank)	0	0.00%
Grand Total	**208**	**100.00%**

No matter what ethnicity the respondents belonged to, value for human life was a common feature. Every human being had their own place and space that could not be replaced by anyone else. 115 respondents (55.29%) agreed to human beings having

intrinsic value, 93 (44.71%) people did not agree to human value being intrinsic, 2 respondents said they could not decide.

QII. These sets of questions were multiple-choice questions. Respondents selected the most appropriate answers from the list that was provided to them.

Table II (a): Why a patient may request euthanasia?

Your personal reason why a patient might request euthanasia		
Responses	**No. Of Responses**	**Percentage**
1. Dignity of self	62	30.10%
2.Right to die as a fundamental constitutional right	17	8.25%
3.Depressed with the situation	62	30.10%
4.Due to being alone/loneliness	14	6.80%
5.Treatment is too costly	37	17.96%
6. Any other reason that you can think off	14	6.80%
(blank)	0	0.00%
Grand Total	**206**	**100.00%**

Respondents were asked what will be the most appropriate reason that patients might ask to have their life terminated. 62 (30.10%) persons *Dignity of self* and *Depressed with the situation* could be the reasons that one might request for euthanasia. 37 (17.96%) persons felt as treatment is too costly patients would rather die than continue treatment that they could not afford. 17 (8.25%) participants agreed that dying according to ones will, was a fundamental right, (made them aware that as of now it is not a fundamental right in India to die like some countries in the world that have legalized euthanasia). Only 14 (6.80%) persons felt that loneliness could be a reason to consider euthanasia. 14 (6.80%) persons remarked there could be other reasons that they are not aware off. 4 persons said they could not answer this question.

Table II (b): Why should euthanasia not be legalized?

Your personal reason why euthanasia should not become legal.		
Responses	**No. Of Responses**	**Percentage**
1. Caretakers might abuse their rights on a patient due to their own vested interest	64	32.00%
2. Patients will lose trust in medicine and physicians	29	14.50%
3. Due to ambiguity in the laws	29	14.50%
4. Patients will give up fight for survival, if there is an alternative given	50	25.00%
5. There is a chance of the slippery slope situation, since who will decide where and how to stop a patient from being put to death	22	11.00%
6. Any other reason that you might like to	6	3.00%

mention		
(blank)	0	0.00%
Grand Total	**200**	**100.00%**

As the discussions on euthanasia were for and against legalizing the act, a question why euthanasia should not become legal was a valid point that needed to be addressed.

The first remark that was made by every participant in the interview discussion that they all felt terminally ill patients will be at a risk of neglect and then lead to eventual death as they are weak and vulnerable. 64 (32.00%) persons felt that caretakers might abuse their rights on a patient due to their own vested interest. 50 (25.00%) respondents felt that patients will give up fight for survival, if there is an alternative given. 29 (14.50%) persons felt that patients will lose trust in medicine and physicians. 6 (3.00%) persons believed there can be other reasons. 10 persons felt reluctant to answer this question.

Table II (c): What other options can be given to a patient if euthanasia is denied?

When a patient requests for euthanasia and not granted permission, what other options should be provided to a patient?		
Responses	**No. of Responses**	**Percentage**
1. Go back and continue with the medication.	40	19.32%
2. Let death come naturally.	74	35.75%
3. Look for other methods of treatment.	82	39.61%
4. Any other option that you can think of.	11	5.31%
(blank)	0	0.00%
Grand Total	**207**	**100.00%**

If the request of the patients for euthanasia is not granted, what are the options they can resort to? 82 (39.61%) of the respondents felt that they should *look for other methods of treatment.* 74 (35.75%) *Let death come naturally*. 40 (19.32%) *Go back and continue with the* medication. 11 (5.31%) felt there should be other options that they were not aware of available in case where euthanasia was not granted. 3 persons did not respond.

Q.III. On Palliative Care

This study is based on the theory that Palliative care is the only answer to euthanasia; the survey was a tool to help the researcher find if palliative care was the right approach to combat the dying requests. Hence it became important to add this segment in the survey. Palliative care was defined in the survey and since this was a discussion and interview survey questionnaire, and a detailed explanation of Palliative and Hospice care was given to every person that filled out the survey form which also added an awareness of the end of life care options.

Table III (a): Will awareness of Palliative care be a welcome option?

Do you think if there is awareness about Palliative Care, it will help patients to rethink their option on ending their life?		
Responses	**No. of Responses**	**Percentage**
I Agree	196	93.33%
I Disagree	14	6.67%
(blank)	0	0.00%
Grand Total	**210**	**100.00%**

This is the only question that every respondent answered. 196 (93.33%) persons agreed to the fact that if there was an awareness a lot of patients that were suffering till the very end of their life would benefit. 14 (6.67%) persons did not feel it will be helpful for patients to rethink their end of life options even if they were aware of Palliative care.

Table III (b): Will patient want to continue to live if they get love and importance?

Do you think if a patient is given the same love and importance as before the illness was diagnosed, a patient will want to continue to live?		
Responses	**No. Of Responses**	**Percentage**
I Agree	187	90.34%
I Disagree	20	9.66%
(blank)	0	0.00%
Grand Total	**207**	**100.00%**

An answer to this question was given a lot of thought by most respondents. Some of them felt that if a patient was suffering, they would not consider if they were loved or important. As many understand that death is a journey that one has to decide for themselves. Some felt that love is a very strong emotion; it can make a human endure any amount of pain. 187 (90.34%) persons felt that if a patient is given as much as importance before their illness they will strive to live. 20 (9.66%) persons disagreed to this theory. 3 respondents felt that this question was irrelevant to a terminally ill patient because if they have decided to terminate their life they will do so regardless of their surroundings.

Table III (c): Do you think palliative care is an answer for some euthanasia requests?

Do you think Palliative Care is an answer to some, if not all, euthanasia request?		
Responses	**No. Of Responses**	**Percentage**
I Agree	199	95.22%
I Disagree	10	4.78%
(blank)	0	0.00%
Grand Total	**209**	**100.00%**

199 (95.22%) participants felt that palliative care will be helpful. 10 (4.78%) felt that palliative care was not a necessary answer. 1 respondent was not sure as he said that until this survey, he did not know that something like palliative care even existed, had he known so, he would have had an opportunity to provide his ailing mother suffering from cancer a better and somewhat pain-free death.

Some Suggestions by the respondents.[1]

- Euthanasia is justified in cases the patients are terminally ill as it relieves prolonged pain and if death is the better option, then the patients' wish should be respected.
- Euthanasia should not become legal because it would hurt and cause mental pain to the patients who may have the will to live in spite of their suffering.
- I feel euthanasia is the right decision for a patient with critical illness because it is distressing for the patient as well as the family members to see the patient in so much pain and suffering. It is just a measure to give easy death to the patient.
- Personally, from the moral perspective I do not support euthanasia however I do support giving people an option to empower them to make their own choice, I support palliative care.

Important Findings of the Survey

Analysis of the study: The survey had mixed responses with 116 respondents agreeing to legalize euthanasia with strict laws in place. The major concern for the general public regarding legalizing *EPAS* is the misuse of it for the benefit of surviving members of a patient. Loneliness and depression due to the illness will be a major reason for ending life requests. During the discussion interviews, observations were made that if people are

[1] Maintained the exact language and spelling of the respondents of their suggestions.

given the time and opportunity they don't fear to speak about their innermost inhibitions on death.

The key answers of the respondents that highlight the value of human life is visible in the survey and gives us a factual understating of what one may desire at the end of their life -

- 58.74% respondents stated that they will lose trust in their physicians.
- 55.29% felt that humanity has intrinsic value.
- 32% felt that caretakers will abuse their rights on patient.
- 62% people felt that dignity of self and depression would be the overarching reason for requesting to die.
- 93.33% felt that palliative care will allow patients to rethink their options when seeking death as an alternative.
- 90.34% agreed that if care was provided they would want to continue to live.

Most importantly the rationale quest was answered: if patients are given the care with love and compassion they will want to continue to live, if not all, at least most of them?

Respondents benefit: Respondents were satisfied at the end of the survey as they gained knowledge of Palliative and Hospice Care. One major change about the survey was that respondents were aware of end of life actions in medical institutions but were not aware of the terms used; also it helped the respondents to learn about the advance directives. Making them well aware that palliative care strives to provide a pain free death, not of curing their illness but to allow them to live comfortably even in their suffering and towards their end of life.

Cicely Saunders idea of caring for the suffering is very relevant in our context: "Suffering is only intolerable when nobody cares. One continually sees that faith in God and his care is made infinitely easier by faith in someone who has shown kindness and sympathy." (Richmond, 2015).

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