



Review article

Physician assisted suicide in dementia: A critical review of global evidence and considerations from India

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ABSTRACT

Background: Dementias are a group of gradually progressing neurodegenerative conditions, leading to significant impairment in cognition, functioning, decision-making, capacity and autonomy. With the rise of human rights and patient-centred perspectives in psychogeriatric management, physician-assisted suicide (PAS) has emerged as an important and integral part of end-of-life care in advanced dementias.

Methods: With only few original studies in the area, this paper takes a narrative and critical approach to review the global legislations, treatment decisions, debates as well as perspectives from patients, families and medical professionals.

Results: PAS and euthanasia are legally allowed in countries like Belgium, Netherlands, Switzerland and few states of the United States (U.S.). Germany has fewer clearer legislations in this regard. The Oregon state requirement and care criteria of the Dutch euthanasia act form the basis of most such laws. Even in the presence of these provisions, PAS is fraught with multiple medical, ethical, moral and legal dilemmas and physicians as well as caregivers are quite heterogeneous in their outlook. While right to live with dignity and need to end incurable suffering form the main arguments for PAS, several arguments against it are possibility of undue influence, impaired judgement leading to biased decision-making such as depression and suicidality, inappropriate assessment of capacity, and that all deaths are not necessarily painful. These dilemmas are critically discussed in light of autonomy, decision-making and advanced directives in people living with dementia as well as the rationality of ending life and 'right to live vs right to die'. Based on the findings, certain balanced strategies are highlighted for the health professionals.

Conclusion: The 'slippery slope' of PAS needs to be carefully evaluated from a social justice and human rights perspective to improve dignified end-of-life care in dementia. Considerations are also discussed from India, a rapidly-ageing nation with no current provisions for PAS.

1. Introduction: the burden of dementia

Dementias or major neurocognitive disorders are a group of neurodegenerative disorders characterized by progressive impairment in cognition, behavior, and functionality (World Health Organization, 2020). Other neuropsychiatric symptoms like depression, anxiety, apathy, irritability, agitation, etc. are commonly present, irrespective of the type of dementia, referred collectively as the Behavioural and Psychological Symptoms of Dementia (BPSD) (Cloak and Al Khalili, 2021). Globally, approximately 43.8 million people were living with dementia in 2016, an increase from 20.2 million in 1990. Dementia is found to be the fifth leading cause of mortality (Nichols et al., 2019). Patients with

dementia show a gradual loss of functioning skills and capacity for decision-making over time (Harrison Denning et al., 2019). The presence of BPSD, independently as well as along with the cognitive impairment, worsens outcome, quality of life, functioning, and capacity in dementia (Cerejeira et al., 2012; Gather and Vollmann, 2013). Activities of daily living (ADL, including instrumental ADL or IADL) are often compromised, along with cognition and other neuropsychiatric symptoms, more so in the later stages of the illness (Sadock et al., 2017). Inability to perform ADLs leads to an increased need for assistance from the caregivers (Desai et al., 2004). Besides, the elderly often suffer from several medical comorbidities, causing further impedance in functioning. Almost 60 % of patients with dementia are seen to suffer from three or

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more medical illnesses. Medical comorbidity is seen to increase with the severity of dementia and has an adverse impact on the cognition of the patient. (Doraiswamy et al., 2002) As dementia progresses to the so-called end-stage, there may be profound impairment in motor, speech, cognitive functions, leading to inability to perform basic life-sustaining activities like eating, dressing, toilet activities, etc (NIA, 2017). End-stage dementia, however, is not manifested by an abrupt functional change and may last for two to three years. Caregiving for end-stage patients can be challenging and is often associated with poorer social and occupational engagement, and depression. (Allen et al., 2003) All of these may give rise to increased caregiver burden (Allen et al., 2003; Desai et al., 2004) which, in turn, hinders the caregiving role and may precipitate elderly maltreatment, or result in increased long-term care placement (Sadock et al., 2017). End-of-life care (ELC) denotes support to a person suffering from the late stage of any illness, including dementia, to help the person live “as well as possible” till death (Alzheimer’s Society, 2021). ELC decisions become important in cases of dementia to cater to the well-being, dignity, and needs of both patients and caregivers (Allen et al., 2003).

In the steadily increasing aging population, it is of utmost importance to devise and implement comprehensive plans for dementia care. In the same context, another area that remains largely undiscussed is the concept of physician-assisted suicide (PAS) in dementia. Besides the continued debate about its scope, capacity, and legalization, there can be several social, moral, ethical, legal, and human-rights underpinnings to the entire concept. With this background, this paper provides a narrative overview of the available evidence in this regard, critically analyses the dilemma of PAS, and highlights few considerations from the Indian context, one of the fast-aging nations. The aim of this review is not to look at the decision of PAS in a binary fashion but to provide a balanced evidence-based perspective that encourages understanding of this controversial concept and further research. Though the construct of PAS has been critiqued for the inclusion of “suicide” in it and a replacement with “physician assisted death” is suggested by many (Peruzzi et al., 1996), for the sake of simplicity this review will use both these terms interchangeably.

2. Methods

It is important to note that in the absence of much original research in this field, this review has taken a narrative approach. Four major databases (PubMed, SCOPUS, Google Scholar, PsychINFO) were searched with terms “physician-assisted suicide”, “physician-assisted death”, “physician-assisted dying”, “euthanasia”, “assisted death”, “assisted dying” along with “dementia”, “neurodegenerative disorder”, “Alzheimer’s disease”, “palliative care”, and “end-of-life care”. These keywords were used in various permutations and combinations to provide maximum and diverse yet related results. The search was conducted on 30th April 2021 and all articles available published till that date were included. We did not adopt a limited timeframe as PAS is an ever-evolving concept with growing impetus in the recent decades. Since this was not a systematic review, we wanted to broaden our arena of search for maximal inclusion. After screening the abstracts, the authors independently went through the articles in entirety and cross-referenced for additional resources. Only papers which discuss PAS / assisted death in any type of dementia or legislations pertaining to the same were included. All types of articles were included for this qualitative review considering the limited number of empirical papers. The findings are presented and critically discussed in the following sections for the sake of clarity. We first review the various legislations globally available related to PAS, how PAS in dementia stands out to be different, critically weigh the evidence both for and against assisted-dying and finally discuss the role of physicians in the process and the scenario in India. Certain recommendations for deciding for or against PAS are also highlighted based on this discussion.

3. End-of-life care in dementia and physician-assisted death: provisions in various countries

End-of-life care (ELC) support encompasses all domains of living, including physical, emotional, and spiritual. ELC may extend to the caregivers and family even after the death of the patient (Alzheimer’s Society, 2021). This brings in the concept of a “good death” which means death with dignity, in and around familiar places and people (Alzheimer’s Society, 2021). While talking about the wish for a dignified death, it is reasonable to think of a person’s voluntary will for assisted death. Physician-assisted death is often defined as consisting of both euthanasia and physician-assisted suicide (PAS) (Goligher et al., 2017). The latter term is controversial in itself and there has been growing discourse on its replacement with ‘physician-assisted death or dying’ as suicide more often refers to the voluntary taking away of one’s own life. The National Health Service (NHS), United Kingdom (UK) defines euthanasia as the act of deliberately ending a person’s life to relieve suffering and PAS as the act of deliberately assisting another person to kill themselves (NHS, 2018). The difference lies in the degree of physician involvement according to one study (Porter and Warburton, 2018) and in the agency primarily responsible for the causation of death in another (Khan and Tadros, 2013). In euthanasia, it is the medical professional or a third person, whereas, in PAS, it is the patient himself/herself (Khan and Tadros, 2013). In this review, we would focus on PAS. To avoid controversy, PAS will denote physician-assisted death throughout the manuscript and the authors would urge the readers to look beyond just the literary implications of these terms. People considering PAS are seen to do so mainly for reasons including loss of autonomy and capacity to perform basic functions of daily living, severe intractable pain, unbearable suffering due to a chronic progressive terminal illness like cancer, end-stage organ failure, neurological diseases, dementia (Gather and Vollmann, 2013; Wiebe et al., 2018). In advanced dementia, patients are often disabled in terms of mobility, eating, bathing, grooming, personal hygiene, pain, incontinence, or disability due to medical illnesses, leading to loss of autonomy to varying degrees, extreme dependence on the caregivers, and insurmountable suffering (NIA, 2017), that might give rise to a wish for an assisted death.

The legal provisions of PAS are different in different countries. Among the countries legalizing PAS to variable extents are Switzerland, Oregon, and Washington states of the United States of America (US), Netherlands, Belgium, Luxembourg, New Zealand, and Canada (Gather and Vollmann, 2013; Steck et al., 2013; Rada, 2021). Spain has recently passed a bill decriminalizing PAS and euthanasia in case of chronic and incurable illness causing intolerable suffering (Rada, 2021). The regulations covering PAS in these nations also vary quite a lot. In the Netherlands, Belgium, and Luxembourg, unbearable suffering without a scope of improvement is needed to appeal for PAS. The US states include the mandatory presence of a terminal illness. (Steck et al., 2013) In Switzerland, the mentally ill are not excluded from the PAS provision, when the wish to die is not a part of a treatable mental condition. (Steck et al., 2013) As per a report of the right-to-die organization “Exit Deutsche Schweiz”, approximately 80 % of the assisted suicides had at least one incurable medical or neurological disease, cancer being the most common underlying diagnosis as in the Netherlands and Oregon. In the Swiss Federal Statistical Office report, 3% of cases had depression and 0.3 % had dementia (Federal Statistical Office, 2016). An analysis of death records from the forensic institutes of Switzerland by Bartsch et al. reported the prevalence of 30.7 % of neurological disorders (1.4 % with Alzheimer’s dementia, 4.3 % with Parkinson’s disease) and 13.1 % of psychiatric illnesses among the assisted suicides (Bartsch et al., 2019). In 2010, the “Exit Deutsche Schweiz” reported carrying out PAS for four cases of unspecified dementia. In the Netherlands, the cases of dementia documented to undergo PAS had an atypical course and possessed intact mental capacity at the time of carrying out PAS (Gather and Vollmann, 2013). Since Oregon regulations require the presence of a terminal illness leading to death in six months, neuropsychiatric illnesses are

commonly not covered, though some associated dementia may be present in patients with “other illnesses” (Gather and Vollmann, 2013; Steck et al., 2013). Among countries having strict rules against the sanction of PAS, Germany is one. Their law as well as the medical code of ethics oppose PAS. However, more than half of the German population, in a survey, was found to be favoring the legalization of PAS though only 6.2 % of them mentioned considering it for themselves in the specific scenario. (Gather and Vollmann, 2013) It has also been reported that a part of the German population wishing for PAS often traveled to Switzerland for carrying it out due to the restrictive law in Germany (Fischer et al., 2008). The physicians’ opinions in Germany regarding PAS were also varied (German National Ethics Council, 2006). Likewise, a survey among the members of the Royal College of Psychiatrists, UK, revealed that there is an increase of 2.5 % in the number of members feeling a need to change the current legislative prohibition of PAS in the UK, though most of them did not favor participating in PAS (Porter and Warburton, 2018). A similar picture is seen in a study among the Indian medical practitioners, only a quarter of whom supported the idea of physician-assisted death in certain incurable and terminal conditions (Abbas et al., 2008). But another survey in 2011 in a tertiary care hospital showed around 70 % of the doctors to be in favor of physician-assisted death in cases of intolerable pain and suffering (Kamath et al., 2011). The judiciary professionals were found to support euthanasia strongly, whereas doctors had a mixed attitude, with those in palliative care opposing the most (Singh et al., 2016). One survey in San Francisco revealed conflicting opinions regarding PAS among people with disabilities (Fadem et al., 2003). These differing views among the general population, physicians, and the governing bodies on the matter of PAS further contribute to its controversial status, more so in dementia where capacity and onus are important factors to play.

4. Physician Assisted Suicide (PAS) in dementia: how is it different?

The mandatory prerequisites for a decision of PAS are adequate information, the person’s capacity to understand, appreciate, weigh the information and to make a decision, voluntary choice, and complete autonomy (Hegde and Ellajosyula, 2016). Any clinical condition impairing capacity temporarily needs to be treated and capacity reassessed (Peruzzi et al., 1996; Orentlicher et al., 2016). With dementia, the difficulty lies in the fact that capacity is often irretrievably lost, especially in the later stages of the illness, which may repudiate the justification of PAS. The decline of language, behavior, memory, executive function, and metacognition, important for decision-making and awareness, is noted across different types of dementias (Gleichgerrcht et al., 2010; Wilson et al., 2016; Darby and Dickerson, 2017). Psychiatric comorbidities are commonly present, including depression, psychosis, apathy, behavioural symptoms, which may hinder capacity for rational decision (Garcez et al., 2015; Woodrow et al., 2019). What’s also vital is that this decline in the capacity is on a continuum and at no point can it be considered as an absolute construct! However, the diagnosis of dementia itself does not legitimize the conviction of incapacity. Capacity is considered to be task-specific. (Hegde and Ellajosyula, 2016) There have been studies demonstrating no significant restriction of capacity in the majority of mild dementia patients on MacArthur Competence assessment Tool, though capacity was less than the healthy controls (Moye et al., 2004). But it has been agreed upon across the literature that eventually most of the patients with dementia lose their capacity to consent over the course of the illness (Gather and Vollmann, 2013). A report from Oregon in 2011 showed an inability to participate in enjoyable activities, loss of dignity, sense of burdensomeness, loss of autonomy, loss of control over bodily functions as various causes reported by assisted suicides (Mendelson and Bagaric, 2013). All of these are more often encountered than not by patients with dementia. This brings us to certain ethical and medico-legal dilemmas related to PAS in dementia which are presented as follows.

4.1. How autonomous is autonomy?

It has been argued time and again that autonomy is not absolute. Individual autonomy is almost always influenced by various other factors like family, social relations, past experiences, culture, education, occupation (Gather and Vollmann, 2013; Hegde and Ellajosyula, 2016). This may be even more pertinent in patients with dementia who may be largely dependent on their social relations for various needs (Gather and Vollmann, 2013). Autonomy and voluntary choice are said to be compromised if there is any form of strong influence from other individuals, like caregiver, family, or physician (Beauchamp and Childress, 2019). If the decision is taken due to any condition impairing judgement (as a part of psychopathology), that cannot be termed as autonomous. For example, the wish to die in patients with depression. Older people with dementia are considered much more vulnerable than younger adults to external influences. Thus, came the concept of “substantial autonomy” (Beauchamp and Childress, 2009), that is reasonable autonomy exercised during decision-making in the specific situation, devoid of any significant influence, either external or illness-related.

Besides, autonomy and capacity are both sides of the coin. Understanding the context and implications of the PAS decision are vital for the individuals, irrespective of external influences. Assessment of capacity eventually needs to be in the context of the particular decision in question as already mentioned earlier (PAS in this case). Referred to as the “gatekeeping role” in medical ethics (Beauchamp and Childress, 2009), decision-making capacity with respect to an illness usually has these dimensions which need to be considered for PAS as well (Fadem and Beauchamp, 1986; Appelbaum, 2007; Beauchamp and Childress, 2009):

- Express and implement an informed choice
- Comprehend the information provided and ability to reproduce the same in their own words
- Appreciate the illness/disorder with which the person is affected, the curability, symptoms, and possible benefits of available treatment
- Ability to process and utilize the medical information (contextualized based on his/her own life, assess risks vs benefits of any decision regarding the illness, appreciate its consequences)

From an ethical viewpoint, it is best to consider a person retaining his/her decision-making capacity as long as possible respecting his/her autonomy without placing him/her at risk of non-autonomous decisions. Also, this ‘capacity’ is a continuum and can even be temporarily affected in dementia, without necessarily being contributed by the neurodegenerative process per se (example: delirium) (Müller and Walter, 2010).

4.2. Right to life vs right to death

In the majority of the countries across the world, basic human rights include the right to life. Though suicide or a person’s infliction of death to self has been decriminalized in most of the global laws, the step is purely humanitarian and still upholds the right to life. (Mendelson and Bagaric, 2013) Assisted suicide, thus, may be equated to homicide or culpable homicide, since the right to die or to cause death to another does not exist. Hence the idea of right to life is a rigid one whereas right to life with human dignity incorporates the humanitarian and individualistic views, that become important in dementia. (Mendelson and Bagaric, 2013; Article 21 of the Constitution of India - Right to Life and Personal Liberty, 2015; Constitution of India, no date) This bifurcates into an important dilemma. Should the right-to-life in people, suffering from intolerable distress and disability due to an incurable illness, be endorsed at the cost of their dignity? Or should the liberty of the person, in this specified scenario, to end his/her own life be respected?

4.3. Rationality of ending life

The decriminalization of suicide, including in the [mental healthcare act \(MHCA\) \(2017\)](#) in India, has followed the idea that the person attempting or committing suicide has been under severe stress ([Wittwer, 2013](#); [Sneha et al., 2018](#)). This presumption argues against the rationality of such a wish and thus, the capacity of the person. Several philosophical arguments against the rationality of suicide have also been proposed over time by Kant, Fritze, Camus. However, the validity of none of these arguments is rock-solid. There are various factors to consider while deciding whether it is rational to end one's life. The factors include the quality of life of the sufferer, disability and activity restriction, loss of dignity, and irreversibility of the disability, to name a few ([Schramme, 2013](#); [Wittwer, 2013](#)). The personal opinion or biases about irrationality is considered redundant while evaluating another person's situation ([Schramme, 2013](#); [Wittwer, 2013](#)). However, in dementias, the ability of this 'rational' understanding and decision on ending one's own life itself can be compromised.

4.4. Wish for PAS in a person suffering from dementia: how consistent is it?

In mild or moderate stages of dementia, when personal autonomy and decision-making capacity are intact, patients may opt for PAS in a future scenario of incapacitation. Advanced directives about PAS in people with high risk for dementia (strong family history) is also a possibility in case they do not want to bear the suffering, lack of autonomy, and dependency of advanced dementia stages. Yet there is a possibility that the person's views may change over time with adjustment to the altered situation, even in the face of worsening cognitive function ([de Beaufort and van de Vathorst, 2016](#)). The wish or advanced directive for PAS may be revoked as long as the person is deemed to have intact capacity. But once incapacity sets in, there is no way to know beyond doubt the wishes that the person has. Enabling PAS in presence of the patient's wish to continue to live may not have legal repercussions in such cases in the states where PAS is legalized, but it surely violates the ethical and moral responsibilities.

The consideration for caregivers and family cannot be over-emphasized in PAS. Only 5% of the primary caregivers of terminally ill patients in a study had discussed the option of PAS with the physician, and 2.5 % hoarded the drugs. ([Emanuel et al., 2000](#)) Less than 40 % of caregivers of end-stage cancer patients in another study supported physician-assisted death ([Yun et al., 2011](#)). The various factors influencing the caregiver and public attitude towards PAS include economic condition, religiosity, type of illness of the patient, experience, cultural beliefs ([Emanuel et al., 2000](#); [Worthen and Yeatts, 2000](#); [Frey and Hans, 2016](#)).

One pertinent concern that needs discussion here is the increase in the number of deaths in areas legalizing PAS ([Steck et al., 2013](#)). One out of five people undergoing assisted death in the Netherlands did not give explicit consent ([Smets et al., 2009](#)). The rate of non-voluntary euthanasia was found three times higher in Belgium than Netherlands ([Pereira, 2011](#)). One survey revealed 66 out of 208 physician-assisted deaths in Belgium to be without explicit consent ([Chambaere et al., 2010](#)). The reasons mentioned were the inability to give consent due to coma or dementia ([Pereira, 2011](#)). It is also recorded that almost 50 % of all the cases are not reported in Flanders, Belgium ([Smets et al., 2010](#)). Despite the ethical and moral obligations of not carrying out euthanasia or PAS in patients unable to give voluntary autonomous informed consent ([Gather and Vollmann, 2013](#)), these statistics raise the suspicion of medical paternalism of another form and possible abuse or misuse of the opportunity by people with a vested interest.

5. Role of physicians and mental health professionals with regards to PAS

One of the major problems in deciding the role of a medical professional in PAS is the moral and ethical dilemma associated with the basic tenets of the profession and the conflicting demands of PAS ([Jakhar et al., 2021](#)). The transition from administering a life-saving agent to a life-ending agent is a difficult one and thus has been discussed time and again with no conclusion reached. Acts of PAS can be both that of omission and commission, i.e., either administration of a lethal medication (eg, lethal dose of morphine or sedative) or withholding life support respectively (eg, ventilator or nutritional support) ([Abohaimed et al., 2019](#)). In a review ([Barsness et al., 2020](#)), only 7% of the 150 US medical and surgical societies were found to have an explicit positional statement on PAS. Most of them (45 %) opposed PAS, 36 % had positions of studied neutrality; 18 % acknowledged PAS without a position. Those opposing PAS state that non-maleficence and beneficence, two core principles of medical ethics, are breached by it and thus inconsistent with a physician's professional role. ([Barsness et al., 2020](#)) On the other hand, [Krones and Richter \(2006\)](#) argue that since the role of the physician is to treat a patient according to his/her self-determined will, the assistance in their death is ethical from the physician's perspective if the illness is terminal and incurable and dying becomes the only means of escape from this unbearable suffering ([Krones and Richter, 2006](#)). The debate arises where the subtle grey line can be drawn in a psychologically burdened patient when impaired 'judgement' makes him/her take active steps to commit suicide. However, the American Academy of Neurology (AAN) mentions in their positional statement a physician's principal duty of healthcare and palliative care provision, as well as the patient's right to end-of-life care decision ([Russell et al., 2018](#); [Barsness et al., 2020](#)). The AAN recommends the physicians to "relieve the suffering" and "respect the wish" of dying patients, in their 2018 position statement, in congruence with the prevailing law of the state ([Russell et al., 2018](#)). They, however, preferred to use the term "lawful physician-hastened death" instead of PAS to emphasize 'death to relieve suffering'. As part of the safeguarding protocol, the state of Oregon requires, for PAS, the presence of a terminal illness, intact decision-making and self-administration capacity, two assistance requests made to the physician in a span of 15 days, written request co-signed by two witnesses, adequate information regarding alternatives of PAS, psychiatric assessment in case of any possible mental impairment, and continuous monitoring of the practices ([Hendin and Foley, 2008](#); [Emanuel et al., 2016](#)). But no globally accepted guideline is available regarding PAS, let alone PAS in dementia. The American Psychiatric Association (APA) in their position statement in 2016 prohibited the administration of any intervention by any psychiatrist to a non-terminally ill person to cause death ('[APA Official Actions Position Statement on Medical Euthanasia](#)', 2016; [Salkin, 2017](#)). There has not been any specific mention of dementia in it.

The clinician needs to have an active role in coordinating between the person with dementia and family members, with an assessment of capacity and symptoms at each stage. Frankly, there are no absolute right or wrong choices. In terms of decision-making capacity, it is recommended: "not to set the bar for the patient too high, so that it is unattainable" ([Faden and Beauchamp, 1986](#)). The mode of PAS also deserves mention due to the irreversibility of death by some means and the possible physical and psychological complications if the PAS is unsuccessful. Importantly, the "voluntary" aspect of the decision for PAS needs utmost emphasis and all situational and contextual influences need to be taken into account so that it is not coercive. Patient autonomy is of fundamental importance and socio-cultural influences need to be considered ([Faden and Beauchamp, 1986](#)). As per [Gather and Vollmann \(2013\)](#), the physicians themselves might knowingly or unknowingly end up influencing the patient's decision for PAS by either "manipulation of information", biased presentation of information, and psychological impact of the patient-doctor discussions. This can impact both for and

against the decision for a PAS (Gather and Vollmann, 2013). Hence, in every case of PAS in dementia, it is vital that the physician must enable the family make an informed choice by educating them about all possible pharmacological and psychosocial interventions available at that stage of the illness. It also needs to be ascertained if the people in question have been adversely influenced by any external agencies or family members. The bottom line is that the person should be competent at the time of decision-making for PAS and understands the methods and consequences of its execution. The area of 'competence' is probably the most distinguishing area of PAS. It cannot be denied that the physicians in question will undergo a plethora of moral, religious, ethical, and medical dilemmas themselves in the process of PAS, and hence it is often suggested that a team of physicians stay involved along with an independent clinician who has not been involved in the prior treatment of the patient (Hufen, 2010; Gather and Vollmann, 2013; Beauchamp, 2019). Ganzini et al. (2000) in their survey of US forensic psychiatrists showed that the more the "ethical reservations" of the participants against PAS, the greater thresholds were put forward by them to validate the patient's decision-making capacity for PAS (Ganzini et al., 2000). Physicians are but humans and their core values and learnings can be highly heterogeneous thus influencing this abstract and debatable construct of PAS. To summarize, in the words of Gather and Vollmann (2013), if the PAS request of an individual is "sufficiently autonomous, well-considered and stable", preventing the person from carrying out his/her wish can be "hardly justified" on ethical or legal grounds, respecting the self-dignity of the patient (Gather and Vollmann, 2013). However, there need to be clear and standardized guidelines for the same inclusive of the role of every specialty involved in the PAS team.

After reviewing the existing literature on opinions and conflicts of the health professionals, including both physicians and psychiatrists, and the evaluative aspects relevant for PAS in dementia, we hereby set forth some possible considerations for the assessment and management discourse in cases requesting for PAS, in line with Oregon state requirement and due care criteria of the Dutch euthanasia act (Buiting et al., 2008) (Table 1).

6. The ambiguous scenario in India

In line with the global rise in the aging population, the number of elderly in India is also scaling up. In the Indian scenario, the prevalence of dementia is 1% in people aged 60 years and above, as per the first wave of the Longitudinal Aging Survey of India (LASI) (International Institute for Population Sciences (IIPS) et al., 2020). The number of older people (above 60 years) is expected to rise to 19.5 % by the year 2050 which also entails increase in the number of dementia cases (International Institute for Population Sciences (IIPS) et al., 2020; Government of India, no date). Despite such a large number of people living with dementia, the service gap for dementia is around 90 % as per the ARDSI report, 2010 (KS et al., 2010).

Article 21 of the Constitution of India states that "no person shall be deprived of his life or personal liberty except according to procedure established by law" (Constitution of India). In cases of M.S. Dubal Vs state of Maharashtra, P. Rathinam Vs Union of India, the Bombay High Court, and the Supreme Court concluded that the right to life as per Art. 21 includes right not to live as well. On the other hand, in cases of Chenna Jagadeeshwar Vs state of Andhra Pradesh, Gian Kaur Vs state of Punjab, the respective courts ruled out the right to die as part of the sanctioned rights under the Constitution. (Chenna Jagadeeswar And Anr. vs State Of Andhra Pradesh on 16 April 1987, no date; Maruti Shripati Dubal vs State Of Maharashtra on 25 September 1986, no date; P.Rathinam vs Union Of India on 26 April 1994, no date; Smt. Gian Kaur vs The State Of Punjab on 21 March 1996, no date) The Indian Penal Code (IPC) has penal provisions for murder, culpable homicide, attempt to murder or culpable homicide, attempt to or abetment of suicide (s. 299, 300, 302, 304, 306, 307, 308, 309), and any act to end the life of oneself or another fell under the purview of a criminal offense until 2017

Table 1

Do's and Dont's for the healthcare professionals regarding physician-assisted suicide (PAS) in dementia.

DO'S	DONT'S
<ul style="list-style-type: none"> Detailed evaluation of the patients, including cognitive, psychiatric, medical, psychosocial, environmental assessments. Assessment of patient's premorbid and current cultural, religious, spiritual values and beliefs. Assessment of values and beliefs of the caregiver/family/social system. Identification, and rapid management of any modifiable cause of suicidality i. e. depression, psychosis, behavioural symptoms Detailed assessment of patient's current decision-making capacity, including understanding, appreciation, reasoning, and communication (use socio-culturally sensitive tools of assessment wherever appropriate) Assessment of any possible manipulation/coercion/ any other act interfering with patient autonomy, and ensuring the voluntariness of the patient's PAS request (eliminate undue influence) Provision, to both patient and family, of detailed information about the end-of-life care options, both pharmacological and non-pharmacological, residential care options Maintaining respect for patient's autonomy and dignity during communication Ensure the patient's involvement as much as possible Multidisciplinary approach, involving patient, family, and professionals from fields of medicine, psychiatry, law, social work, and relevant administrative bodies Documentation of relevant information and discussion in detail, including the reason for patient's request of PAS, presence or lack of alternatives, mode and administration of PAS, etc., with assessments done preferably by two independent medical professionals, including one mental health professional Mental health professionals may have an additional role in addressing conflicts, dilemmas and improving the adjustment and well-being of the other professionals involved Continue dignified healthcare and end-of-life support till any decision of PAS is made 	<ul style="list-style-type: none"> Not to determine the threshold of capacity for autonomous decision-making based on personal values, beliefs, or biases. Not to use a 'generic or general' rule for all Not to provide selective information. Not to manipulate the presentation of information to facilitate any preconceived direction of decision. Not to disrespect or undermine either patient or family's concerns Not to prioritize either the physical or the psychosocial distress at the cost of deeming the other insignificant Not to undertreat comorbid medical, surgical, or psychiatric conditions To avoid both excessive patronization and professional nihilism Not to violate the medical code of ethics or law prevailing in that country/state Not to bring in individual biases/ perspectives/opinions while making the PAS decision Not to take a decision of PAS single-handedly

(Indian Penal Code, 1860; Jakhar et al., 2021). With rising concerns about human rights in the several petitions and cases requesting assisted death, the issue of euthanasia gained more attention and discussion over the years. The first euthanasia regulation bill, proposed in 2002, suggested "compassionate termination of life of persons completely and permanently invalid or bed-ridden by the incurable disease", later rejected by the Parliament (Government of India, 2012). Another subsequent attempt by the Indian Society of Critical Care Medicine in collaboration with the Law Commission of India in 2005 drafted a bill focusing on passive euthanasia for the terminally ill. This was also denied by the Government of India because of the possibility of legalizing suicide (Shekhawat et al., 2018; Jakhar et al., 2021). Then came the landmark case of Aruna Shanbaug, who stayed in a persistent vegetative

state (PVS) for 42 years before dying in 2015 of pneumonia, with her appeal for euthanasia rejected by the court. As a part of the verdict on this case, a five-judge bench of the Supreme Court announced the legalization of passive euthanasia, on 9th March 2018, by the withdrawal of life support for patients in PVS ([Passive Euthanasia Now a Legal Reality in India, 2018](#)). The prime debate was between acceptance of death only as an automatic form of destiny (considering life belongs to the state) versus the violation of right to live with dignity. Active euthanasia or PAS is still not legal in India. However, “living wills” or advance directives related to requests for passive euthanasia made in a sound mind need to be respected.

The current provision in India does not allow any person with psychiatric illnesses including dementia to undergo assisted death unless brain-dead or in PVS. Thus, unwillingness to continue living on account of loss of dignity is not a legal pretext for requesting assisted death. Though dementia care in India has evolved over the last decade, considerations for ELC and PAS in dementia have unfortunately not been discussed in scientific literature or policies. India also has a socio-culturally and ethnically heterogeneous populace with a large socio-economic divide. PAS and euthanasia being abstract concepts with moral and religious underpinnings, there can be several belief systems attached to the same ([Sinha et al., 2012](#)). These are often different for active and passive euthanasia, with numerous arguments and sentiments centred for and against them, that are beyond the scope of this paper. It also depends on media portrayals and social stereotypes related to death, dying and destiny. In 2018, a report from Reuters mentioned that the issue of euthanasia is not considered “politically contentious in India” though it can spark millions of different socio-cultural and religious dilemmas ([Menon and Mohanty, 2018](#)). As in other parts of the world, there is divided opinion among medical staff regarding PAS in India. A recent survey by [Kalal et al. \(2020\)](#) among 90 nursing officers working in the ICU setting showed that while more than half had a neutral attitude towards euthanasia, 47.7 % had a favourable response. The response was not associated with their professional and demographic variables ([Kalal et al., 2020](#)). Interpretative qualitative studies are warranted to further understand the in-depth attitudes of people towards PAS in a diverse nation like India, and the belief systems that guide them.

The [Mental Healthcare Act \(MHCA\), passed in 2017](#), marked a paradigm shift of approach towards mental health from the previous act. It is patient-centred and right-based, in line with the United Nations Convention on the Rights of Person with Disabilities (UNCRPD) ([Rao et al., 2016](#); [Math et al., 2019](#)). Another major positive change endorsed by the MHCA is the decriminalization of suicide in section 115, repealing the s. 309 IPC ([Sneha et al., 2018](#)). However, this act does not have any clause specifying the needs of the elderly with mental illness and is surprisingly silent on the rights-based perspective of a dementia patient. Advanced directives are incorporated into MHCA as the documented wish of a person, with intact capacity, regarding the way he/she wants to be treated in case of the onset of any future mental illness. But the option of physician-assisted suicide in case of intolerable suffering and loss of autonomy in dementia is not provided for, explicitly or implicitly ([‘Mental Healthcare Act, 2017’, 2017](#)). Multiple challenges are noticed in the drafting and implementation of advance directives, at the level of clinicians, patients, caregivers, and judicial and administrative bodies. Poor literacy, insufficient access to information, lack of knowledge regarding mental illnesses and their management options are a few of the barriers. Though the Apex Court has provided recommendations for writing advance directives in cases of expected terminal illness/ incurable coma, dementia has not been counted in ([Philip et al., 2019](#)). Keeping in mind the current gap in the implementation of advance directives in overall mental illnesses, similar provisions for PAS are not likely to come to the forefront any time soon. On the other hand, palliative and end-of-life care in India is far from satisfactory, especially in dementia. As per the Dementia India Report by ARDSI in 2010, there are only 10 day-care centres, 6 residential care facilities, 6 domiciliary

care facilities, and 10 dementia helplines for patients with dementia all over India ([KS et al., 2010](#)). With approximately 4.1 million people in India currently living with dementia ([Alzheimer’s Disease International \(ADI\), 2015](#)), this is unlikely to be sufficient. Around 50–70 % of patients are seen to need care and 40–70 % of primary caregivers report having psychological morbidities. Lengthening living without meeting needs may lead to several psychosocial issues, including worsening of the clinical condition of the patient, caregiver burnout, elder abuse, poor living condition, high financial burden ([Kumar et al., 2019](#)), ultimately culminating in the loss of ‘self’, autonomy, and dignity of the patient. Stigma and discrimination against elderly with dementia, lack of adequate awareness and education among both patients and caregivers, dearth of policies and programs specifically designed to address the long-term care needs in dementia add to the difficulties ([Kumar et al., 2019](#)). Another facet is the family value in Indian society. The Indian society and families are collectivistic, promoting interdependence, cooperation, and social cohesion. Thus, families constitute an important resource in the social support of patients with mental illnesses, including dementia ([Chadda and Deb, 2013](#)). PAS may not be in keeping with these traditional family values. Also, religiosity may have a significant bearing on people’s views on suicide ([Sharma et al., 2013](#)). It is important to address all the legal, ethical, moral, societal, and cultural conundrums, keeping in mind the basic right of patients of dementia to have a voluntary autonomous decision-making opportunity regarding living with dignity. A collaborative effort of all the disciplines concerned with dementia is needed to build awareness among patients, caregivers, health professionals, lawyers, and care organizations, as well as to mobilize the discussion on the provision of PAS in advance directives.

7. Conclusion: the way ahead

It follows from the review that there is no single-stop solution to the issue of PAS from the perspective of physicians. Also, even though there are legislations in this regard in various countries, there is continued ambiguity in the role of mental health physicians in PAS. The question of whether life belongs to a person, family, or state cannot be indisputably answered. But approaching the problem from a human rights point of view is equally necessary. Dignified healthcare is considered to be a necessary right and end-life decisions fall within its purview. Right to life should not be equated to an obligation to live, at the cost of failing physical and mental health, and unbearable suffering with no possibility of improvement. The authors do not recommend mandating PAS, but rather emphasize that a person, with intact capacity to take a voluntary autonomous decision on when and how to end his/her own life in case of unchangeable future health deterioration, should have an option of doing so and the physician needs to be involved throughout the process in coordinated care. Thus, a patient in the early stages of dementia may specify in advance directives regarding choosing PAS when his/her autonomy gets compromised in a more advanced stage leading to excessive dependence on others for basic activities of daily living including self-care. The capacity and the autonomous and voluntary nature of the decision should be evaluated and attested by independent professionals, including at least one mental health professional, trained in the same. Structured capacity assessment tools need to be supplemented by socio-culturally relevant clinical assessment and triangulation of information from various sources to rule out undue influence. This is where the need for clear policies comes into the picture. It will be vital to prevent role ambiguity and fear of medico-legal complications in physicians. The patients and their families should be educated regarding and offered ELC options. In a rapidly aging nation like India with an increasing dementia burden, it is imperative to start a collaborative dialogue regarding PAS between people living with dementia, their caregivers, psychiatrists, neurologists, palliative care experts, general physicians, dementia care public health agencies, judiciary bodies and finally the policymakers. Further research is needed to reflect the comfort, understanding, and choices of both physicians and patients/

caregivers of dementia with regards to PAS in their own voices. The palliative care facilities should be strengthened in India, both in terms of quality and quantity. Awareness campaigns and support groups for caregivers need to be actively promoted by Governmental and non-Governmental organizations. There will be a continuing debate on the ethical and legal validity of PAS, but eventually, it is not about the “right to live or die”. In a world where mental health has moved towards human rights and social justice-based approach, it’s about improving the end-of-life quality of care in people living with dementia, respecting their choices, autonomy, and dignity.

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