an approach is not at the expense of authentic emotional engagement with a patient. On the contrary, such a professional framework is more likely to facilitate a true empathy bounded by the security of clear professional boundaries and limitations on the actions a clinician is permitted to undertake. This is important as the emotional climate of care at the end of life can blind the clinician to the factors driving a patient's desire to die. This is exemplified by the clinician who assumes that a "rational" choice (i.e. one that the clinician can understand as reasoned) equates with "capacity". This is illustrated in the impact of depression on evaluation of risks and benefits of treatment choices — to underestimate benefits or value through a depressive lens of pessimism, loss of meaning and self-worth.

A key element to the clinical context of end of life decision making is the psychology of the doctor-patient relationship at end of life, providing as it can the fertile ground for enactment of clinician biases about what constitutes quality of life and meaningful continuation of life.[11] As Hendin has argued, deciding when a patient is to die can be "seductive" in giving the clinician the illusion of mastery over the disease and (their) accompanying feelings of helplessness.[12] This is especially relevant alongside the ample evidence indicating the difficulties experienced by clinicians in discussing death, existential concerns and assessing the psychological needs of their dying patients.

Contrary to Beauchamp's assertion regarding the "good doctor," this does not mean refusing to help, but most importantly, helping the patient through the often difficult task of supporting physical comfort, adapting to the personal upheaval invoked by advancing disease, the fears and concerns for themselves and their families, and the deep but often unspoken existential dread of facing death. This is done, over centuries, without necessitating the doctor's actions to intentionally end a patient's life. To consider the ethical issues in isolation from these critical clinical perspectives and realities will confront the very limitations in the practical application of such ethical principles so aptly highlighted by Mendz and Kissane.

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## Response to a 'Commentary' and Letters

**Dear Editor,**

It is surprising that Professor Beauchamp in his 'Commentary'[1] states that "The article contains little on agency, autonomy, assisted suicide, or euthanasia" when a whole section in that study[2] is devoted to describe agency, including a definition (p. 556), and another section discusses the concept of autonomy and a definition is given (p. 557). Human agency involves the exercise of freedom in self-governance to achieve competent control and the unencumbered intentionality as we initiate actions in our lives. Agency is always subject to internal and external influences. True agency is only realized when these influences are explicated by the exercise of judgement, with insight into these influences and related choices, and by an appreciation of how any decision impacts upon the life of the person.



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It is important for the reader to understand that agency and decisional capacity are not the same, nor are agency and autonomy, nor decisional capacity and autonomy. Autonomy is founded on both agency and decisional capacity, the absence of either of these would result in lack of proper autonomy.

Indeed, important decisions arise in what Professor Beauchamp terms "last-resort situations." The comparison between a person who requests euthanasia and a person who jumps from the Trade Center applies insofar as they seek a specific action as their only escape, but it does not carry in full. First, the circumstances of their decisions are significantly different. In jumping from the Trade Center, a person is placed in an impossible physical situation beyond her/his control, and to this extent, the predicament is autonomy-undermining. The situation of a person requesting euthanasia as a solution is not a physical impossibility, but a psychological one which becomes autonomy-undermining. Secondly, the reasons for their actions could be surmised as very different; to jump was not necessarily with the intention to commit suicide and die, but to avoid burning and/or asphyxiation, whereas the person requesting euthanasia seeks death itself. The circumstances and the intentions of the actions make them very different.

Controlling influences are invariably significant in such circumstances and can act as a tipping point for any judgement. Making explicit any such ambivalent tensions around a decision is key to the clinical appraisal. We have proposed a method which seeks to understand the minimal conditions for autonomy through assessment of agency: is the judgement supportive of *autonomy-conferring* self-governance or is the judgement resultant from *autonomy-undermining governance?* Our thesis does not refer exclusively to situations where underlying mental conditions compromise agency, but that the impairment of this internal capacity in whatever life circumstances can hinder and impede the personal exercise of autonomy.

Consider the example of a woman with advanced cancer drawing closer to the end of her life. Does she accept MAID now because her child impatiently wants to return overseas, or later because her husband lovingly wants more time with her? To the legal mind, this choice may appear black or white; to the clinical mind, family dysfunction is evident and undesirably influential. When a mother proposes to sacrifice her life altruistically to benefit her child while hurting her husband, to consider whether her judgement is autonomy-conferring or autonomy-undermining proves helpful. The loss of her life is a profound tipping point under intense family influence.

Does a man who perceives his body to be decaying access MAID to relieve his suffering? His thinking could appear reasonable until his nihilistic delusion is recognised, that is, that the decay is out of proportion to clinical reality and a false belief that he carries. Treatment of his psychotic depression could successfully ameliorate his suffering. Examining the agency of these subjects is a crucial step. The autonomy-undermining characteristic is a vital consideration alongside any compassionate desire to relieve suffering.

Referring to last resort situations, Professor Beauchamp's view is that "The good doctor may be the one who benevolently helps the patient in these situations, not the doctor who refuses to help while lacking adequate evidence of incapacity." Professor Kelly In his letter[3] comments that a medical practitioner has "a responsibility to work to understand and address, where possible, sources of suffering and distress" with "an approach [that] is not at the expense of authentic emotional engagement with a patient." He emphasises that "This is important as the emotional climate of care at the end of life can blind the clinician to the factors driving a patient's desire to die. This is exemplified by the clinician who assumes that a 'rational' choice (i.e. one that the clinician can understand as reasoned) equates with 'capacity'." We agree with Professor Kelly's understanding that this "does not mean refusing to help, but most importantly, helping the patient through the often difficult task of supporting physical comfort, adapting to the personal upheaval invoked by advancing disease, the fears and concerns for themselves and their families, and the deep but often unspoken existential dread of facing death. This is done, over centuries, without necessitating the doctor's actions to intentionally end a patient's life."

Professor Beauchamp concludes his commentary by identifying the 'bigger' problem, that not all cases of MAID are justifiable. Rather than leave this for another day as he suggested, our quest has been to point to the assessment of agency as helpful to establish autonomy. Such agency is lived in relationship to the other, where free will can empower creative love amid experiences and rituals of trust, freedom, and generativity. Forfeiture of agency reduces creativity and generativity and is associated with poor decisions, impeding human growth and the capacity for love.

In response to our article about how diminished agency potentially reduces autonomy in a decision to undertake physician-assisted suicide, Drs Sweet and Blanke[4] emphasized that referral for counselling in Oregon is only required if a patient's mental disorder causes impaired judgement. Such impaired judgement is but one example of impaired agency; loss of


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agency does not arise exclusively in persons with some underlying psychological conditions, but also in individuals with no psychological disturbances who find themselves in "last-resort" situations. Conversely, we do not state that all patients with some psychological conditions (those mentioned in the study and others) have lost their agency. Our article presented four situations, which were discussed as examples of the much deeper issue of potential loss of agency. How this is done will depend on the specific circumstances of each individual. There are tests to assess agency, but the best way is in a personal conversation with an appropriate health care professional with necessary expertise. The kernel of our argument is that individuals may not have impaired decisional capacity but lack proper agency, and thus lack autonomy.

The need to avoid potential burdens for a patient does not counterbalance the need to establish her/his proper autonomy in what can be a matter of life and death. We proposed the fundamental need to establish true agency not because of our views on euthanasia or assisted suicide, but because of the fundamental respect owed to the autonomy of each individual.

We would agree that there is an important difference between views and biases, because if the views of persons who do not agree with MAID are broadly characterised as biased, the same would apply to those of persons who advocate for MAID. The protection of the physical and psychological integrity of individuals ought not be set aside as burdensome. Physically weak persons as well as those terminally ill should be afforded more care and protection, not less, as an appeal to expedite processes may require.

It remains a curious fact that only 1 in 188 persons in the 2019 Oregon Data Summary was referred for mental health evaluation. Drs. Sweet and Blanke's assertion that many patients were prescribed anti-depressants and mental health referrals, and did not ingest the lethal medication is very interesting; a comment that suggests counselling and medications appear to be an effective means to resolve the mental and physical difficulties persons may have at a given point in time rather than prescribing a lethal medication.

Returning to the central issue of our study, loss of agency is not circumscribed to mood disorders, and certainly not just to depression. There are many influences upon agency and only by making these explicit can we ascertain the true autonomy of a person. Yet much of the legislation relating to euthanasia or physician-assisted suicide has been silent about agency. We commend to readers the evaluation of whether the reasoning that gives rise to any behavior is *autonomy-conferring* or *autonomy-undermining* because such assessment will reveal much about the preservation of true agency.

*George L. Mendz and David W. Kissane*

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