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### Care of the older person and the value of human dignity

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#### **Abstract**

As the world population is rapidly aging, stakeholders must address the care of the elderly with great concern. Also, loss of dignity is often associated with aging due to dementia, mobility problems and diminished functional autonomy. However, dignity is a polysemic term that is deemed useless by some ethicists. To counter this claim, we propose four concepts to define it better and make use accurately of this notion. These are human dignity, dignity of identity, dignities of excellence and attributed dignities. Finally, we explain the importance of solicitude and human dignity in the care of the elderly. This will ensure the respect, friendship and dignity of the elderly in providing geriatric ethical care.

#### KEYWORDS

care, dignity, ethics, geriatrics, solicitude

#### 1 | INTRODUCTION

According to the World Health Organization, the older population is increasing 'at an unprecedented pace and will accelerate in coming decades, particularly in developing countries'. Providing care in such a context will face challenges in maintaining respect towards the frail and older person. In many Western healthcare institutions, the elderly with reduced capacity often face disrespectful attitudes from doctors and nurses.<sup>2</sup>

Even though the value of dignity is set to be the foundation of the Universal Declaration of Human Rights, the use of dignity in bioethical debates is still controversial.<sup>3</sup> Because of various possible interpretations, dignity has been used in opposing senses. Some suggest that this concept is too slippery to tackle difficult problems in bioethics.<sup>4</sup> It is used to justify the legalisation of euthanasia for suffering patients but also mentioned as a reason to avoid euthanasia

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<sup>&</sup>lt;sup>1</sup>World Health Organization (WHO). (2022). *Aging*. Retrieved November 31, 2022, from https://www.who.int/health-topics/ageing#tab=tab\_1

<sup>&</sup>lt;sup>2</sup>Nordenfelt, L. (2009). Dignity in care for older people. Blackwells.

<sup>&</sup>lt;sup>3</sup>Cochrane, A. (2010). Undignified bioethics. *Bioethics*, 24(5), 234–241. https://doi.org/10. 1111/j.1467-8519.2009.01781.x; Macklin, R. (2003). Dignity is a useless concept. *British Medical Journal*, 327, 1419–1420.

<sup>&</sup>lt;sup>4</sup>Kuhse, H. (2000). Is there a tension between autonomy and dignity. *Bioethics and Biolaw*, 2, 61–74.

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for the most vulnerable of them.<sup>5</sup> Others have accused dignity of a rhetorical gesture to stall biomedical progress.<sup>6</sup> Moreover, some suspect that dignity is redundant, a term that simply restates other ethical principles, such as respect for autonomy.<sup>7</sup>

Despite the philosophical controversy, the concept of dignity is persistent in biomedical practice. It is, in fact, a growing area of research in healthcare fields like palliative care. As a relevant concept in the day-to-day experience of the elderly, it appears inevitable. We still have much to learn from the tangible patient experiences. Hence, 'How does dignity apply to the elderly when treated as having equal status?' and 'What factors contribute to the denial of the dignity of the sick and frail?' one might ask. Healthcare professionals often have only a vague idea of what it means to respect one's dignity when providing care, especially for the elderly. Caring is central for most geriatricians as frail vulnerable patients need more care than cures, dementia and other illnesses of old age being incurable. Hereafter, vulnerability must be met with compassion. 11

In this paper, we explain four types of dignity, determine what aspects of dignity apply to the elderly, how dignity relates to caring for fragility and what the implications are for geriatric care. Caring often trumps curing in geriatrics. Neurodegenerative diseases afflict more frequently the elderly. Frailty and reduced life expectancy call for adapted care, which aims at comfort rather than prolonged survival. We know that an older adult with multiple diseases does not need to be aggressively treated but rather requires a secure environment with compassionate healthcare professionals. As the body and mind age, having meaningful and thoughtful relationships is instrumental to respecting one's dignity. Some conceptions of dignity are non-attributive in that it is not gained nor lost, whereas other conceptions are attributive in that it is obtained based on excellence or in personal history and can deteriorate.

We want to draw attention to the fact that in geriatric care, there is a danger of losing dignity, as it is tied to excellence. In Western society, ageism, ableism and mental health stigma tend to depreciate the elderly suffering from dementia. At the same time, there are ways to maintain the dignity of elderly people if we understand it as respecting the identity of the person, her personal history and future, with all her relationships with other human beings.

# 2 | BACKGROUND: CLINICAL PERSPECTIVE ON DIGNITY IN RELATION TO THE GERIATRIC CARE

We should then examine how such concepts could translate into practice. As the elderly are at more risk of having a medical condition, more need for care is often the burden of advanced age. Hence, we need to answer the following: 'What is dementia? What are multiple comorbidities? What is frailty from a geriatric perspective? What is the difference between caring and curing in geriatrics? Is "loss of dignity" a concept to be forgotten? What is the threat of "dementophobia" in our Western societies?'.

## 2.1 | Geriatrics and vulnerability of the older person

First, we must define dementia. The American Psychiatric Association newly described the major neurocognitive disorder (MND). <sup>12</sup>To have a diagnosis of MND, one must display a cognitive decline in one or more domains of cognition, which are complex attention, executive functions, learning and memory, language, perceptual-motor or social cognition. Cognitive decline must interfere with at least one activity of daily living (ADL). These are related to managing complex tasks, such as paying the bills, using a computer, driving a car, etc. The patient should not have a diagnosis of active delirium nor any other mental disorder such as depression, schizophrenia or others that can mimic MND. Then, as the diagnosis is given to a patient, the clinician should specify the type and if there is behavioural disturbance associated with it. That would be a mood disorder, psychosis, paranoid idea, apathy or other.

Another concept that needs to be considered when caring for the elderly is a higher risk of having multiorganic conditions affecting the brain and nerves, heart, kidneys, lungs, and so forth when aging. Another way of defining this is frailty. This relatively new concept in geriatrics is evaluated through different means. Two well-known models are used to define frailty. First, the cumulative model states that each deficit leads to more frailty. The Fried's frailty scale is one of the well-studied examples of this measurement and based on grip strength (lowest 20% of a given population), endurance (walking slower than 20% of people that are the same age), weight loss of 10 pounds or more, low level of activity. A loss of one or more of these domains results in being frailer. This is a cumulative model of frailty because the accumulation of deficit results in frailty. Secondly, another model is based on frailty phenotypes. As the elderly are affected by the loss of autonomy and mobility, frailty rises. This is based on Rockwood's Clinical Frailty Scale. Medical and mobility problems and/or loss of functional autonomy are considered to calculate frailty from a clinical perspective.

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<sup>&</sup>lt;sup>5</sup>Pageau, F. (2020). La responsabilité de protéger les personnes âgées vulnérables. Presses de l'Université Laval.

 $<sup>^6\</sup>text{Pinker},$  S. (2008). The stupidity of dignity. The New Republic, 28(05.2008), 28–31.  $^7\text{lbid}.$ 

<sup>&</sup>lt;sup>8</sup>Barclay, L. (2018). Disability with dignity: Justice, human rights and equal status. Routledge; Chochinov, H. M. (2012). Dignity therapy: Final words for finals days. Oxford University Press; Cf. Pageau. op. cit. note 5.

<sup>&</sup>lt;sup>9</sup>Nordenfelt, L. (2003). Dignity and the care of the elderly. Medicine, Health Care and Philosophy, 6, 103–110; Nordenfelt, L. (2004). The varieties of dignity. Health Care Analysis, 12, 69-81; Ternestedt, B. M. (2009). A dignified death and identity-promoting care. In L. Nordenfelt (Ed.), Dignity in care for older people (pp. 146–167). Wiley-Blackwell.

<sup>&</sup>lt;sup>10</sup>Barclay, L. (2016). In sickness and in dignity: A philosophical account of the meaning of dignity in health care. *International Journal of Nursing Studies*, 61, 136–141.

<sup>&</sup>lt;sup>11</sup>Fiasse, G. (2015). Amour et Fragilité. Regards philosophiques au cœur de l'humain. Presses de l'Université Laval.

<sup>&</sup>lt;sup>12</sup>American Psychiatry Association (APA). (2013). Neurocognitive disorders. In American Psychiatry Association (Ed.), Diagnostic and statistical manual of mental disorders (5th ed.).

TABLE 1 Caring versus curing.

#### Caring:

- Relational
- Safe space
- Adapted to comorbidities/cognition (understanding)
- Compassionate healthcare

#### Curing:

- Treating/eliminating a disease
- •Biomedical perspective /expertise first
- Life-saving
- Not considering comfort so much

The first model is more often used in research, and the second one is used in clinical settings. These scales are proxies of frailty evaluation since the gold standard is the Comprehensive Geriatric Assessment (CGA). This contains a medical assessment (problem list, comorbidities, medication, nutritional assessment), functional assessment (basic ADL, gait and balance assessment, activity assessment) and psychological assessment (cognitive status, mood). The CGA also relies on a social evaluation (informal social support) and environmental appraisal (care resource eligibility/financial assessment, home safety and access to transport facilities). This multidomain evaluation helps to diagnose and care for the frail elderly.

As humans, we are all vulnerable because we are at risk of disease and are mortal; hence deserve care. <sup>13</sup> The older person is often considered as vulnerable in the literature. <sup>14</sup> However, some older adults are more vulnerable than others <sup>15</sup> as they suffer from MND and/or frailty. These lead them to be more vulnerable in a multilayer way <sup>16</sup> shown by the frailty indexes and the CGA. This was found in the previous literature. <sup>17</sup> Should we treat the elderly as any other adults? How is care even more important in geriatrics? This is considering that equality of care should not be based on vulnerability as a broader concept, as we are all vulnerable <sup>18</sup> but on a more specific view, that is frailty in geriatrics.

#### 2.2 | Care and cure

In geriatrics, healthcare providers aim to integrate the biomedical science of curing with human care. The psychosocial aspects are required, as well as the biomedical ones, as shown by the CGA. So, how may one define care and cure as distinct concepts? Curing aims to treat or eliminate the disease. It is based on the biomedical

perspective, placing medical expertise and knowledge first. Any lifesaving intervention is deemed essential, even trumping comfort. By contrast, caring is ingrained in relationships, and compassionate healthcare also considers the patient's perspectives and emotions; hence, creating a safe space and providing care adapted to comorbidities and mutual understanding is the basis of caring (cf. Table 1).

Dementia care represents a specific type of care in geriatrics. As MND progresses, care must be adapted to cognition, loss of autonomy and frailty. So, the objectives of care are more palliative than lifesaving amidst a curing perspective. Also, the medical team works more often on preserving comfort than life.

#### 3 | THE FOUR CONCEPTS OF DIGNITY

In dementia care, there is a need for a secure environment that is safe and compassionate as the cognitive decline progresses. Meaningful and thoughtful relationships help to respect one's dignity in dementia care. <sup>19</sup> However, pertaining to people with dementia, loss of their dignity due to the MND and related symptoms is often put forth as an inevitable consequence of the disease. Nevertheless, is this accurate that a human person can lose dignity? We need to reinstate a better vision of dignity to understand if this is the case. We suggest four concepts to better understand how attitudes of respect for dignity can play out in dementia care.

#### 3.1 | Human dignity

The first concept of dignity that we analyse is *human dignity*. This is the best-known and the most discussed concept of dignity. We assume that human dignity is an intrinsic worth of the natural kinds of humans. It is a supreme worth which is grounded by the constitutive properties of humans. Hence, vulnerability, MND and/or frailty can never reduce nor eliminate human dignity.

<sup>&</sup>lt;sup>13</sup>Fineman, M. A. (2010). The vulnerable subject: Anchoring equality in the human condition.
Yale Journal of Law & Feminism, 20(1), Emory Public Law Research Paper No. 8-40, Available at SSRN: <a href="https://ssrn.com/abstract=1131407">https://ssrn.com/abstract=1131407</a>

<sup>&</sup>lt;sup>14</sup>Bozzaro, C., Boldt, J., & Schweda, M. (2018). Are older people a vulnerable group? Philosophical and bioethical perspectives on ageing and vulnerability. *Bioethics*, 32(4), 233–239.

<sup>&</sup>lt;sup>15</sup>lbid.

<sup>&</sup>lt;sup>16</sup>Sanchini, V., Sala, R., & Gastmans, C. (2022). The concept of vulnerability in aged care: A systematic review of argument-based ethics literature. *BMC Medical Ethics*, 23(1), 84.
<sup>17</sup>Ibid.

<sup>&</sup>lt;sup>18</sup>Cf. Pinker, op. cit. note 6.

<sup>&</sup>lt;sup>19</sup>Denier, Y., & Gastmans, C. (2022). Relational autonomy, vulnerability and embodied dignity as normative foundations of dignified dementia care. *Journal of Medical Ethics*, 48(12), 968–969.

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There are some traditional ways of characterising human dignity: the Aristotelian idea of humans as rational animals, the Christian idea of humans as being images of God, and the Kantian idea of humans as autonomous agents. We can add here Martha Nussbaum's<sup>20</sup> idea that humans have a specific set of basic capacities that grounds human dignity. However, we do not settle for any of these positions. What is crucial to human dignity is that it belongs to humans to the same degree and that it can never be lost. Every human has dignity (an intrinsic worth) from birth to death, even if they are frail, have dementia or live with a handicap.

#### 3.2 | Attributed dignities

Some worth of humans might be called attributed dignities. The most salient attributed dignities are the ones that are the result of an explicit nomination, like 'I hereby nominate you to be governor, chair, etc.'. The persons with such explicitly attributed dignities are, in many cultures, often called dignitaries. Some other attributed dignities are only indirectly the result of nominations. These are the hereditary dignitaries, kings or members of nobility, and so forth. The ancestors of these persons have, at some point, been nominated. Some attributed dignities are the result of the awarding of prizes or diplomas. To be a Nobel Prize laureate is also to have dignity. The same holds for distinguished and officially praised authors and artists as well as the acknowledged stars among sportsmen and sportswomen.

This type of dignity is less related to MND or frailty. It is a type of dignity that should not have an impact on care. However, presidents, kings and other dignitaries sometimes may have easier access to care if they are frail or have MND. Their official title might be withdrawn because of MND or other diseases.

#### 3.3 | Dignities of excellence

A third kind of dignity we propose to call *dignities of excellence*. To be an excellent person in a certain crucial respect entails having this kind of dignity. The excellence that sometimes grounds an attributed dignity is the dignity of excellence. There are various kinds of dignities of excellence. The most striking ones are the moral and intellectual dignities. We choose to regard the worth of moral standing as a kind of excellence instead of giving it a category of its own. Still, it is crucial to emphasise the dignity of moral standing as a salient subcategory since it has peculiar characteristics of its own. For instance, morality comes to the fore as a quality of a person's behaviour. The adjectival use of dignity in 'dignified behaviour' often refers to moral behaviour that overcomes social and political

hardships. Dignified conduct is action in accordance with the moral law that expresses an instance of moral excellence. Famous examples are those in which a person sacrifices their life in order to preserve their dignity. Socrates, who was sentenced to death for the alleged crime of having seduced the youth of Athens, decided to remain imprisoned. He thought that he would not have retained his dignity if he had fled. This kind of moral excellence is praised by ancient Greek ethics (Plato, Aristotle) and modernity ethics (Kant).

The intellectual dignities, on the other hand, are the grounds of several attributed dignities both formal and informal: high offices as well as awards and prizes. To these dignities of excellence, we may add aesthetic and athletic ones. These constitute the grounds for artistic achievements as well as achievements in sports. Both attributed dignities and dignities of excellence can change over time, and they can completely disappear. An older person with MND or who is frail may have obtained such a level of dignity of excellence during their life and lost it. This type of dignity comes and goes as their achievement is surpassed or their feat is no longer reachable for them.

#### 3.4 Dignitiy of identity

The fourth category that we propose is the *dignity of identity*. Since no other system that we know of acknowledges this category, at least not in the way we propose, we will now scrutinise it in some detail.

The dignity of identity is the dignity that is attached to us as integrated and autonomous persons with a history, future, and all our relationships with other humans. Most of us have a basic respect for our own identity, although it need not be at all remarkable from social, moral, or other points of view. But this self-respect can easily be shattered, for instance, by nature itself, in illness and the disability of illness and old age, but also by the cruel acts of other people.

Observe that the dignity of identity is not identical with human dignity. We may certainly respect ourselves and others just because we are human. But this is not the respect we have in mind here. We refer instead to the peculiar respect that we have for ourselves and others as individuals with their peculiar characteristics. Thus, crucial factors that ground the dignity of identity are the subject's integrity and autonomy, including his or her social relations. These factors are typically associated with a sense of integrity and autonomy. And when a person's integrity and autonomy are tampered with, this is typically associated with a *feeling* of humiliation or loss of self-respect on his or her part.<sup>21</sup>

But is dignity in this sense, then, identical with a *feeling* or *sense* of worthiness? If we are only talking about a psychological fact, that is, the self-confidence or self-respect of the person, then there is perhaps no need for a special concept of dignity. We here argue for an objective (or at least intersubjective) dignity of identity. The cruel person can succeed in certain things apart from humiliating us. He or

<sup>&</sup>lt;sup>20</sup>Nussbaum, M. (2008). Human dignity and political entitlements. In A. Schulman (Ed.) Human dignity and bioethics: Essays commissioned by the Presidents's Council on Bioethicsi (Vol. 351). Notre Dame Press. https://bioethicsarchive.georgetown.edu/pcbe/reports/human\_dignity/chapter14.html

<sup>&</sup>lt;sup>21</sup>Honneth, A. (1992). Integrity and disrespect: Principles of a conception of morality based on a theory of recognition. *Political Theory*, 20, 187-201.



**TABLE 2** Four categories of dignity.

Categories of dignity	Characteristics
Human dignity	Intrinsic value of an individual
	Never lost even following death, or a disease (e.g., MND)
	Value of any human being regardless of attributes and sense of self
Attributed dignity	Related to a dignitary position such as being a king, a president, or a Prime minister, etc.
	Easily lost if the person has no longer a certain status in society
Dignities of excellence	They pertain to an achievement or a feat in a certain field (art, sport, science, morality)
	Losable if the person is surpassed or incapacitated
Dignity of identity	Associated to our sense of self-worth
	Losable in relation to sense of self-worth or through others' attitude

Abbreviation: MND, major neurocognitive disorder.

she can intrude into our private sphere, physically attack us, and restrict our autonomy in many ways, for instance, by putting us in jail. All these changes are extra-psychological. Some of these are also included in humiliation. They do not just entail feelings of worthlessness or of humiliation. Intrusion in the private sphere is a violation of the person's integrity. Hurting someone may entail a change in this person's identity. The individual is, after this, a human with a trauma; he or she has, in a salient sense, a new physical identity.

To emphasise our contention that the dignity of identity is not wholly dependent on the subject's feelings towards him/herself, consider the following case: An unconscious man or a man with Alzheimer's disease is left naked in the ward of his nursing home. He is left so that everyone around sees him. By himself, he cannot identify the character of the situation. He does not *feel* humiliated. However, his nearest and dearest who find him in this situation can rightly exclaim: 'Our relative has *lost* his dignity in this situation!'.

Although feelings are normally present in forming one's identity, they do not exhaust one's identity. It could be added that feelings need not be present in relation to any of the other types of dignity. This is particularly not the case with human dignity that ex hypothesi is there if a human being exists, he or she is conscious or unconscious. But also, an attributed dignity may be there without the subject acknowledging it. A person may just have been promoted to a position without knowing about it, for instance. And certainly, a person may be dignified in a moral sense without being aware of this or without particularly thinking about it. Of course, also in the cases of these kinds of dignity it is typical that the subject is aware of his or her dignity, but there is no necessary connection.

Consider again the case of cruel acts and their consequences in terms of humiliation. It could be argued that cruel acts, in fact, also violate a person's human dignity. It belongs to the basic human rights of a person to be protected from attacks of various kinds, including humiliating acts. This is true, but this observation does not entail that the two concepts, human dignity and dignity of identity, collapse into one and the same concept. We can immediately observe that humiliation can be the effect of unintentional action but also in such

an accident for which no human being is responsible. We must also bear in mind that humiliation can be the effect of natural events and processes, such as illnesses and aging. A person whose looks have been completely malformed by a disease can feel that he or she has lost her dignity of identity. However, their human dignity is still intact Table 2.

#### 4 | SUFFERING AND DIGNITY

Suffering decreases our capacity to act through various means, and so it affects how people attribute dignity to frail persons. Paul Ricœur has pointed out that suffering should not be reduced to pain (physical or psychological).<sup>22</sup> He emphasises that suffering has an impact on oneself and on our relationships with others.

First, the agent can be powerless in his capacity to speak, and there might be a gap between what he wants to say and his capacity to speak out. When this is the case, we could be attentive to perceiving this person's request or call to be heard. He or she cannot always express what and how much they are suffering.

Second, suffering has an impact on one's capacity to take action. A gap occurs then between what they would like and what they are able to do—in reality. Recognisably, there is always a tension between one's capacities and accomplishments. Moreover, it does not only concern the people who are sick or older. Ricœur refers to humans as being both capable and suffering. Yet, suffering can disrupt the actualisation of capacities—reduce them.

The patient, literally, from the Latin etymology *pati*, is someone who endures suffering. It unfolds in two dimensions. First, there is a passive element in the sense that the disease influences the ills and has power over the person. Second, the suffering fragile individuals with MND also become dependent on others who act on them and for them. They become recipients of care and cure. Still, they can

<sup>&</sup>lt;sup>22</sup>Ricœur, P. (1992a). La souffrance n'est pas la douleur. *Psychiatrie française*, 92, 9-18.

.4678519, 2024, 1, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/bioe.13251 by Readcube (Labtiva Inc.), Wiley Online Library on [02/01/2024]. See the Terms

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experience suffering from the actions of others, such as neglect, mistreatment, and even violence.

We have explained so far that suffering affects the capacity to speak and to take action, which ultimately reduces self-esteem and dignity of identity. For Ricœur, suffering also disrupts the narrative function. He noticed the difficulty for the suffering person to be detached from the moment and to see life as a whole entity. Similarly, as suffering affects the capacity to say or to speak, suffering can become what cannot be narrated. Finally, the person who suffers can hardly esteem one's dignity of identity.

#### Solicitude, care and human presence

A suffering person needs company to regain a sense of agency and dignity of identity (even though both will be of a new sort after enduring pain and suffering) (simplified to 'dignity' only by Gastman<sup>23</sup>). This person's new connection to the world necessarily comprises grief. Therefore, the company of others is needed. Hence, care providers will have to examine themselves under the scope of their own vulnerabilities and potential losses. For example, in the case of MND, one will necessarily be confronted by fragility or brittleness, which is close to frailty but closer to intrinsic vulnerability.<sup>24</sup>

It is, therefore, critical to reflect on these fragilities and frailty to see that we also receive much from others. Even if living in ways that are unique, fragile or vulnerable, people still access something universal to the human condition.<sup>25</sup> These fragilities. brittleness or frailties are shared by all in different ways.<sup>26</sup> The fact that we all inevitably die one day and could lose capacities is of the utmost significance. MND will likely strike anyone who lives long enough. The brittleness of others touches us in our deepest folds. Relationships with other human beings might also be what we value the most. So, it raises the guestion of 'Who will love us unconditionally, until the end?' if we are in such a state of brittleness.

#### 4.2 Moral responsibility

Considering this incapacity increased or caused pain and suffering, it seems important to emphasise that we can nevertheless receive much from suffering people. If we ask ourselves: 'What may I learn by accompanying a person in significant suffering or fragility?' Evidently, we will answer that an individual's suffering gives the caregiver an increased self-awareness of fragility and mortality, 27 but there is more to it than awareness. Our quest for meaning and our capacity to love can be awakened by the other-the one suffering-with our

capacity to love.<sup>28</sup> Unfortunately, Ricœur has not explicitly exposed this concept, nor other philosophers who study capabilities, just briefly mentioned by some like Reader.<sup>29</sup> By stressing our capacity to love, we emphasise that both the suffering people and carers remain able to love. Indeed, as seen with ill or suffering people, the rupture with previous ambitions caused by pain and suffering may lead to being more attentive to the meaning of their lives. Hence, they are more vigilant about the people they love and the love they share.<sup>30</sup> Still, the opposite can occur; a heart attack survivor may feel an urge to live to the fullest without prudence. The fear of death does not necessarily lead to the best behaviours-respect for oneself and others.

Another important aspect is our moral responsibility towards other humans, as well established by Emmanuel Levinas,31 Hans Jonas<sup>32</sup> and Paul Ricœur.<sup>33</sup> Very often, responsibility has been conceived under the model of imputation for which the emphasis is placed on being responsible only for one's actions or actions of subordinates in the role of proxies. Yet there is another element to responsibility. Responsible may be a feeling towards the person for whom one cares. In other words, a person in need can give care providers an amplified awareness of responsibilities.<sup>34</sup> Ricœur even adds the dimension of being made responsible 'because of' some else to the notion of being responsible 'for' some else. 'The fragile person expects our assistance and care', says Ricœur. 35 To him, we are not only responsible for them but made responsible because of them. We are made responsible because of the person who counts on us. Without this other being, we would not have been able perhaps to accomplish many things in life. We are faithful to our promises because someone else trusts us faithfully. However, it is precisely this responsibility 'for and because of' others that can vanish in institutions since there are so many layers between individuals. This dilutes responsibility. Then, no one feels personally responsible for others anymore. This arises when people are satisfied with the completion of tasks and application of the law without any practical wisdom nor real attention to others. Furthermore, this neglect of practical wisdom can increase even more as curing amplified by technology replaces human care. In institutions, there is a pitfall to excessive control and planning. Whereas human action actually happens amid uncertainty and connection between humans. The unpredictability and plurality of human actions were emphasised by

<sup>&</sup>lt;sup>23</sup>Gastmans, C. (2013). Dignity-enhancing nursing care: A foundational ethical framework. Nursing Ethics, 20(2), 142-149.

<sup>&</sup>lt;sup>24</sup>lbid.; Denier & Gastmans, op. cit. note 19.

<sup>&</sup>lt;sup>25</sup>Cf. Fineman, op. cit. note 13.

<sup>&</sup>lt;sup>26</sup>lbid.

<sup>&</sup>lt;sup>27</sup>Cf. Fiasse, op. cit. note 11; Fineman, op. cit. note 13; Bozzaro, C., et al., op. cit. note 14.

<sup>&</sup>lt;sup>28</sup>Fiasse, G. (2012). Ricœur's medical ethics: The encounter between the physician and the patient. In C. Cowley (Ed.), Reconceiving medical ethics (pp. 30-42). Continuum Press; Tronto, J. (2009). Un moment de vulnérabilité-pour une politique du care (H. Maury, Trad.) Édition de la découverte

<sup>&</sup>lt;sup>29</sup>Reader, S. (2006). Does a basic needs approach need capabilities? *Journal of Political* Philosophy, 14(3), 337-350.

<sup>30</sup>Cf. Sanchini, V., et al., op. cit. note 16.

<sup>&</sup>lt;sup>31</sup>Levinas, E. (1985). Ethics and infinity, conversations with Ph. Nemo. Duquesne University

<sup>&</sup>lt;sup>32</sup>Jonas, H. (1984). The imperative of responsibility: In search of an ethics for the technological age. University of Chicago Press.

<sup>&</sup>lt;sup>33</sup>Ricœur, op. cit. note 22; Ricœur, P. (1992b). Oneself as another. University of Chicago Press; Ricœur, P. (2000). The concept of responsibility. An essay in semantic analysis. In P. Ricœur (Ed.), The just (pp. 11-35), The University of Chicago,

<sup>34</sup>Cf. Pinker, op. cit. note 6.

<sup>&</sup>lt;sup>35</sup>Ricœur, P. (1995). Fragility and responsibility. Philosophy and Social Criticism, 21(5-6), 16.

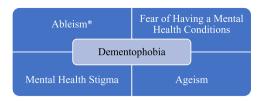


FIGURE 1 Dementophobia.

Hannah Arendt.<sup>36</sup> In loving and being emotionally connected, one is better placed to recognise the personal histories and values of frail persons, that is, their dignity of identity.

#### 4.3 | Dementophobia

Unfortunately, fear of advanced MND or frailty led to hatred during the COVID-19 pandemic. The elderly's dignity of identity was diminished through various means, leading some to believe that there is no dignity nor value left. As an example, the hashtag '#boomerremover' was used on Twitter to describe COVID in a demeaning way for the baby boomers or older adults. Ethicists also underlined the ageism and ableism inherent to a certain vision aiming at protecting the world economy over the elderly. Some suggested that by 'opening up' the economy and reducing measures, we would have saved the economy. This was upheld even if 'saving the economy' meant causing more death and suffering for the old and frail. This would have led to treating humanity as a means rather than an end, notwithstanding human dignity. Then, consider people as means for the good of our economy rather than the reason (ends) why there are financial structures in the first place.

We also suggest that there has been an important level of dementophobia rising lately in Western societies. We define this new term of 'dementophobia' as: 'The intersection of ageism, ableism and mental health stigma that tend to depreciate the elderly with dementia' (Figure 1). Ableism and ageism are discrimination based on handicap or age, respectively. The stigma related to mental health conditions often leads to not only fear but can cause patients not to consult or feel of a lesser value (dignity) because of mental health conditions.

Our society promotes being young, beautiful, healthy, and successful, even for the mere purpose of leisure. Three aspects are, therefore, crucial in this context. First, we should respect the elderly unconditionally, whatever the qualities or achievements that are no longer present and that we highly esteem. These are the features of respect recalled by Arendt.<sup>37</sup> Second, we should not reduce actualisation to accomplishments. Third, we should pay attention to the capacities that the elderly keep despite all losses. The goal is to sustain the person's identity as a moral subject, as a being worthy of memory, respect and regard.<sup>38</sup>

We need to, therefore concentrate on the capacity to love. This can be expressed by a smile, warm touch, nice words and even meaningful silence or song. It is quite surprising to see people with Alzheimer's disease suddenly singing melodies from their youth (tunes never heard by their children). It is necessary for the frail person to supplement for lacking or reduced self-esteem or dignity of identity. Caregivers have to be attentive not only to what the person experiences, but to the individual as a whole (experiences, emotions, actions, and so forth). Therefore, we need to emphasise being mindful in the care of the elderly. It starts with the most basic needs, such as comfort - both physical and emotional.

#### 4.4 | Solicitude or consideration

In this sense, we consider that the pact of care, highlighted by Ricœur,<sup>39</sup> is central to the care of the elderly, especially in hospitals. A certain kind of friendship between the patient and the professional health worker is needed because of the necessity for mutual benevolence. When there is no trust in relationships, the pact of care is disrupted.

Solicitude can provide us with mindful attention to hope in the moment we live in and give us strength to go through our day-to-day lives. We may then consider others truly as we would consider ourselves.

This attention to the moment is a thing that the suffering person can teach us-more than anyone else. There is always a risk of focusing on losses and tragedies instead of positive life events. This situation can be changed by being attentive to the small joys and events of everyday life. The dignity of excellence needs grand moments of accomplishment to actualise itself. To help reckon their own value in terms of dignity of excellence, a person needs to act in a way that brings a sense of self-worth. Yet human dignity recognises the importance of all moments, as small as they may seem, regardless of how amazing (or not in relation to a certain point of view) the person's action is at that moment. In a reply to Peter Singer about children with Down syndrome, Michael Berubé stated that instead of looking at the things people cannot exclude them from our human community, we should look for things 'they can' do. 40 We ought to nourish this positive view of life and frail people in institutions that care for the elderly. One must not forget that the priority is the person for whom to care. Also, one should be reminded that he or she can be part of a team in doing so. Since each one of us needs to be supported by others, this includes healthcare providers. Hence, even if an elderly person cannot eat alone, and can no longer communicate with anyone, he or she remains a human being worthy of respect, cure and care, whatever the capacities or the actualisations that we can see. The value given by human dignity calls for respect, solicitude and friendship in the face of dementophobia.

<sup>&</sup>lt;sup>36</sup>Arendt, H. (1998). The human condition (2nd ed.). University of Chicago Press (Original work published 1958).

<sup>&</sup>lt;sup>37</sup>lbid.

<sup>&</sup>lt;sup>38</sup> Jennings, B. (2009). Agency and moral relationship in dementia. *Metaphilosophy*, 40(3–4), 425–437.

<sup>&</sup>lt;sup>39</sup>Fiasse, op. cit. note 28.

<sup>&</sup>lt;sup>40</sup>Bérubé, M. (2009). Equality, freedom, and/or justice for all: A response to Martha Nussbaum. Metaphilosophy, 40(3-4), 363.

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In the Declaration of Human Rights, dignity was thought to be a protective shield against abuses of power for all human beings and something that can never be lost, but for vulnerable people, that is not enough. In day-to-day life, elderly people are often treated with humiliation for what they do not have anymore: a capacity for self-governing and independence. Stigma and social rejection of people with dementia further increase dehumanisation. Excellence-based dignity, which is inspiring in other spheres of life, contributes to making the elderly vulnerable. However, we can maintain and nourish respect for the elderly if we implement a dignity of identity in geriatric care and keep the notion of human dignity prevalent. Because caring is ingrained in relationships, maintaining meaningful relationships helps to respect one's dignity in dementia care. Suffering affects the capacity to express oneself and diminishes self-esteem. Therefore, geriatric care asks for a presence, friendship and solicitude that help the elderly to regain a sense of agency and self-esteem. A person with MND must be treated with respect relating to other human beings and for the fact that they are still human beings, whatever capacities, or actualisations we can perceive. Cognitive decline makes them lose many values and capacities, but we should recognise their intangible ways of being worthy of respect through human dignity, solicitude, and friendship.

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