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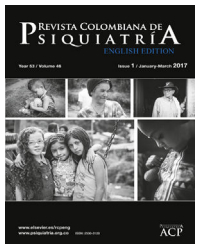

Original article

Dilemmas and ethics of care: conserving and caring for the autonomy of the person with dementia

*Habib Georges Moutran Barroso**

Neurología Clínica, Universidad El Bosque y Fundación Santa Fe de Bogotá, Bogotá, Colombia

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ABSTRACT

Introduction: Dementias constitute a group of diseases that notoriously affect people who suffer from them, especially in terms of their independence and decision-making, leading the caregiver to assume or make various decisions about the patient. However, in the past this was explained by the fact that there was a theoretical and narrative insufficiency around patients with dementia, which led us to ignore that they still conserved their decision-making capacity as well as their autonomy.
Objective: This text proposes to defend the existence of autonomy in these patients and a way about how we can take care of it and preserve it in the medical field, through an ethical position based on the care and recognition of vulnerability.
Methodology: An approach focused on the ethics of care and vulnerability by Ronald Dworkin, Emmanuel Levinas and Corine Pelluchon focused on the person with dementia. I introduced a scale that allows assessing autonomy and decision-making in people with dementia.
Results and discussion: To guarantee the dignity of the person with dementia, it is necessary to understand how they are autonomous, in terms of self-governance and seeking to reduce asymmetries in relationships. In addition, always include caregivers and family members in decision-making.
Conclusions: People with dementia are autonomous in an individual or personal sense and deserve respect; Although they are in a state of vulnerability, there are different mechanisms focused on their care.

Dilemas y ética del cuidado: conservar y cuidar la autonomía de la persona con demencia

Palabras clave:
Autonomía
Dignidad

RESUMEN

Introducción: Las demencias constituyen un grupo de enfermedades que afectan notoriamente a las personas que las padecen, especialmente en términos de su independencia y toma de decisiones, llevando a que el cuidador asuma o tome varias decisiones sobre el

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* *Corresponding author.*
E-mail address: moutranhabib@gmail.com

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paciente. No obstante, en el pasado esto se veía explicado porque había una insuficiencia teórica y narrativa en torno a los pacientes con demencias, lo que conllevaba a ignorar que todavía conservaban su capacidad de toma de decisiones, así como su autonomía.

Objetivo: Este texto defiende la existencia de la autonomía en estos pacientes y una vía acerca de cómo podemos cuidarla y preservarla en el ámbito médico, a través de una posición ética fundamentada en el cuidado y el reconocimiento de la vulnerabilidad.

Metodología: Se realizó un abordaje enfocado en la ética del cuidado y de la vulnerabilidad de Ronald Dworkin, Emmanuel Levinas y Corine Pelluchon centrados en la persona con demencia. Posteriormente introduje un instrumento que permite valorar la autonomía y toma de decisiones en personas con demencia.

Resultados y discusión: Para garantizar la dignidad de la persona con demencia hay que comprender la manera en como es autónoma, en términos de autogobernanza y buscando disminuir las asimetrías en las relaciones. Además de siempre incluir a los cuidadores y familiares dentro de la toma de decisiones.

Conclusiones: Las personas con demencia son autónomas en un sentido individual o personal y merecen respeto; aunque estén en un estado de vulnerabilidad, hay diferentes mecanismos enfocados en su cuidado.

Introduction

Dementia is defined as a major neurocognitive disorder, with a high degree of disability for those who suffer from it. As the disease progresses, the cognitive deficit becomes more disabling, limiting decision-making and many different functions, which means that decisions increasingly fall on the caregiver and family members. However, current literature suggests that people with dementia, even those with a very advanced disease, can have control over different domains of their functioning and self-control over their own lives and, especially, over decision-making, because they can articulate values, preferences and choices according to what they consider important.

Dementia is considered a health problem of vital importance, with implications for carers, public services and healthcare systems, and is one of the most common reasons for admission to residential care homes for older adults. As these people's dependency increases, their care becomes more complex and the importance of preserving and respecting their autonomy, as well as their human dignity, becomes even more pressing. Accordingly, a key message in the World Health Organization (WHO) Report 4 on dementia as a public health priority is the need to improve social, cultural and health perspectives towards, and understanding of, dementia.

People with dementia, despite the burden of the disease, persist in their desire to remain owners and authors of the decisions or processes that directly affect their lives. Therefore, it is an ethical priority to maintain care for this type of people and ensure that they have opportunities to live their lives according to their desires and values, in addition to maintaining their active roles for as long as their illness allows.

Bioethics seeks to address the challenges posed by dementia. It is an interdisciplinary subject that we need to keep constantly abreast of, as well as the different conceptual elements, in order to create bridges in the care of these people and preserve their autonomy as far as is possible. It is a contemporary topic that needs to be discussed, because the prevalence of dementia in the world population has significantly increased, with the WHO estimating that dementia rates will double every 20 years, reaching 115.4 million affected people by the year 2050.[1,2]

It is pertinent to consider decision-making by people with dementia, as well as by their caregivers, because it represents a major challenge, not only in matters concerning medical care (for example, decisions about their treatments as well as preferences related to end-of-life care), but also in those related to their day-to-day concerns, financial aspects and intimate relationships. It is crucial that we take these aspects of people with dementia into consideration, thus raising awareness of the value of their autonomy and sense of well-being.

In this article, I will introduce and defend the premise of the existence of autonomy in the person with dementia, as well as the need to care for them and create action plans based on advance decision-making. To do this, I have used the following categories: dignity; ethics of vulnerability; ethics of care; advance decision-making and personal autonomy. Additionally, I discuss some final considerations about how to care for autonomy in these patients.

Dementia: what are we dealing with?

The word *dementia* derives from the Latin root *demens*, which means "being out of one's mind", and is defined as a syndrome occurring as a result of a central nervous system disease, which is generally chronic or progressive in nature. It consists of the deterioration of several higher mental functions. These impairments are often accompanied by changes in emotional control, social behaviour and/or motivation. Alzheimer's disease and dementia associated with cerebrovascular disease are among the leading causes.

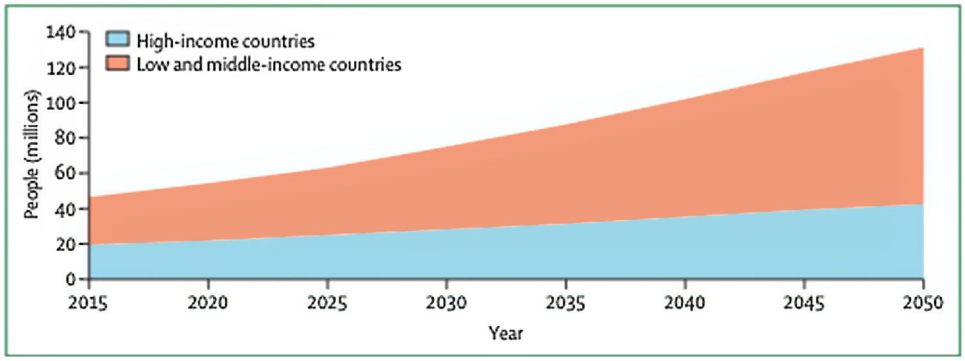

Fig. 1 – Increase in the number of people with dementia in low- and middle-income countries. Source: taken from Livingston et al.[1]

Dementia occurs mainly in people over the age of 65. Worldwide, around 47 million people were living with dementia in 2015, and this number is projected to triple by 2050 (Fig. 1). Dementia causes a person to gradually lose their abilities, with the consequent increase in their dependency and impact on their family and carers. The worldwide cost of dementia in 2015 was estimated at US$ 818,000 million, related to family, social and medical care.[1,2] This figure is expected to continue to grow as the number of people with dementia increases.

Despite efforts to protect older adults, they undoubtedly continue to suffer from age discrimination and insufficient plans to cover their needs, especially in terms of prevention, diagnosis and treatment. Between 2000 and 2050, the proportion of the world's inhabitants over 60 years of age will double, rising from 11% to 22%, and this age group will grow from 605 million to 2 billion over the course of half a century.[3]

In terms of the psychosocial problem of dementia in older adults, the risk of suffering from this condition increases after the age of 65 and the risk doubles every five years. Largely as a consequence of this, in the high-income countries, between 4% and 6% of older people have suffered some form of abuse at home.

In care facilities, such as nursing homes and residential care homes, acts of abuse are committed against these patients, which violate their dignity by deliberately denying them proper care and inflicting physical and emotional abuse. Elder abuse can cause serious physical harm and irreparable psychological damage. It is estimated that, by 2050, a significant number of older adults will not be able to care for themselves, in terms of disability and dependency, and their number will increase fourfold in low- and middle-income countries.[3]

Between autonomy and disability

The term *autonomy* was initially used in ancient Greece to describe cities that governed themselves or created their own laws. The word derives from Greek and does not differ much in its use: *autonomy* comes from the word *autos* (self) and *nomos* (law or rule), and the general idea, which has not changed since then, is that the subject in question, in one way or another, "governs him or herself".

There are multiple ways to be autonomous and, in particular, the category of personal autonomy is ideal for understanding people with dementia. The idea of personal autonomy is that a person "governs him or herself". That is to say, they decide and act according to their own convictions, values and desires, and independently of unwanted internal and external influences.[4] Because, especially when explaining personal autonomy as "self-governance", it is usually implied more by the notion of a "*self*", and that "*self*" is based on the aforementioned idea of a person's own beliefs, values, desires and things. To be autonomous, therefore, one has to decide and act or, to put it in broader terms, live in general according to motives that can count as expressions of one's self, that is, of who the person is or wants to be. Consequently, a person can be classified as autonomous if their decisions, actions, or life in general can be interpreted as an authentic expression of who this person is.[4,5] Therefore, rationality or decision-making capacity are not an exclusive requirement for understanding autonomy, and they are also distinct categories. The challenge of understanding and articulating autonomy—when we are relating to people who have certain limitations—is to be able to account for it in different contexts, such as people with dementia.[6]

People with dementia express interests and make decisions based on these interests, at least until they reach the end stages of the disease, so it is pertinent to preserve and protect the deliberations of these people and for them to be involved in the judgements or decisions made regarding their health and their care, as well as the role of their caregivers. Dependency entails the loss of certain domains of autonomy, but this persists until the end stages of dementia.

Patients with dementia have their past interests, even though their identity, as a psychological and biological continuity, is altered; and they can maintain them in the present, for as long as their condition allows, in order to make political, medical and social deliberations. Excluding what a person expressed at some point is a direct way of attacking their autonomy.

When dealing with a person with dementia, especially in a doctor-patient relationship, it is necessary to keep in perspective that they have needs, just like any other individual, and

the needs of each person vary according to their own context, especially in medical conditions. However, the quality that fosters a better understanding of people with dementia is through the acknowledgement of their state of vulnerability, as their narrative may be affected depending on the stage or progression of the disease. The ethics of vulnerability gives us tools for understanding this scenario, especially the ethics of otherness put forward by Emmanuel Levinas,[7] who posits that, in order to get closer to the *other*, it is necessary to create sufficient means so that the relationships are the least asymmetrical and most empathetic possible, in order to grasp and understand who the person is, as well as what they want. Based on this, we can move towards a therapeutic and problem-solving relationship. Knowing the patient's motivations and desires, both past and present, enables us to make decisions that seek the maximum amount of benefits without undermining or violating their autonomy, and without resulting in any disproportionate measure that causes some type of physical or emotional harm.

Emmanuel Levinas proposes that vulnerability in human dynamics is an asymmetric relationship, because the vulnerable person is limited in one or several ways, depending on a given context. Human relationships are dynamic and must necessarily change in order to respond to the vulnerable person, especially in ethics. Levinas formulates the meaning of "face-to-face" from an ethical principle of otherness, describing an anthropology of empathy that corresponds with the subjectivity of the other, seeking and working on their weaknesses and ensuring that the relationships are the least asymmetrical possible.[7] We should aim to respond to the other by means of communication, because through empathetic recognition we can establish an interpersonal relationship based on dialogue, respect and acceptance of difference.[7]

Dignity and legitimacy

Autonomy is necessarily linked to an understanding of human dignity. In his text "*Autonomy and the demented self*", Ronald Dworkin introduces the issue of autonomy in people with dementia by raising several dilemmas[8]:

Does a competent person's right to autonomy include, for example, the power to dictate that a life-prolonging treatment be denied him or her at a later stage, even if, when demented, he or she pleads for it? Should what is done for a demented person be in his or her contemporary best interests, in other words, to make the rest of his or her life as pleasant or as comfortable as possible? Or should it be in the best interests of the person who has become demented, that is, to make his or her life a better one overall? (Suppose that a demented patient wants a certain care and treatment that would make him or her a serious burden on other members of his or her family—and we believe that people lead better lives when they are not a heavy burden to others—is it in the best interests of the patient, overall, to allow him or her to become the burden that he or she is now anxious of being?)

The category of human dignity is implicitly described in the above paragraph, because it infers that people—despite being in conditions of disability, where there is a decrease in their decision-making ability—can still exercise a domain of agency or local autonomy,[a] expressing what is or is not important to them. Dignity is not lost when there are limitations in the decision-making capacity, because the person retains their autonomy in a particular sense, as well as the right to be considered within social and political deliberations. Autonomy is based on recognition of the freedom that each person has, as well as the capacity that each human being has to self-determination.[9,10]

Dignity, understood as "what is legitimate for each person" in terms of their rights, is necessarily linked to the condition of being human, and this must be upheld and protected, despite the different conditions of vulnerability to which a person may be exposed, especially in psychiatric conditions or dementia.

The way to understand the autonomy of people with dementia is to assume that they are autonomous in terms of self-governance, as I mentioned earlier, and that their capacity for agency, understood as the capacity for action, is not the most paradigmatic. It cannot be deliberately assumed that a person with dementia is not autonomous or does not have decision-making capacity, because to assume this is to ignore their sense of agency and to disregard any desires, thoughts and deliberations they may have. What we need to do for people with dementia is to recognise and seek non-paradigmatic forms of autonomy, recognising that they are agents in a particular sense and that their capacity for action is their own, insofar as it reflects their desires. The premise that should guide the care and attention of these patients is to seek what is best for them and to recognise their local autonomy, as well as their sense of agency.

Ethics of vulnerability

Patients with dementia are in states of vulnerability, given that—as I have mentioned—they have physical, emotional and psychological dependencies on their caregivers, and their decision-making capacity and independence are affected as their condition progresses. However, it has been shown that these patients can make judgements and express thoughts regarding what they consider important to them and select what they want in order to do so. Therefore, as Corine Pelluchon points out, the context of these patients must be orientated based on an understanding of autonomy towards "vulnerability".[11] The "ethics of vulnerability" invites the clinician to discern the context of a vulnerable patient who is deprived of their capacity for judgement or a particular sense of autonomy and cannot account for their emotions or choices. However, this ethic suggests an approach to the ethics of care[11,12] in which healthcare staff appreciate that the affected person is limited and thus provide a holistic care, without this meaning that they lose their moral status.[13] Moral status, as A. Warren suggests, is the disposition to be morally consider-

[a] "The property of a person in which his or her acts or desires are considered individually". This refers to the way in which a person acts in particular situations. At the same time, global autonomy refers to "a type of person who has sufficient properties to exercise control over their own functionalities, or a greater control over their actions, without the need for a third party in order to carry out their work as an agent" (Mullin, 2007).[4]

able before the world, so that the individual cannot be treated as we please, and it is accepted that we are obliged to take into consideration in our deliberations, the needs, interests or well-being of the individual, who is the vulnerable patient in this case. Thus, we are morally obliged to protect the vulnerable, as well as other human beings (particular contexts) and all other things or living beings that are in the natural world.

This ethic takes into account the medical ethics of ethics committees. On the other hand, it invites participants to consider that there may be certain cases that escape these codes, forcing us to accept that there may be an *alterity* (otherness) in autonomy, and this does not always obey the Kantian maxims of rationality. There are many contexts that place patients in a state of vulnerability, but this does not imply that we should posit the univocity of rationality as the maximum requirement for decision-making. Furthermore, stating that a patient does not have decision-making ability entails a great ethical and legal responsibility, because from that moment on the patient loses their legally recognised right to participate in the making of decisions about their health and life.

In this type of context, it is difficult to contemplate only a notion of rational autonomy and the participation of informed consent, which is the hegemony that predominates in contemporary clinical practice. As Carol Gilligan[14] and Corine Pelluchon[11] point out, autonomy is linked to the need to introduce the patient's emotional participation, as well as being an area that seeks to link understanding and compassion from a care approach in the hospital environment. Beyond considering a rational subject, if we contemplate rationality from a Kantian or Rawlsian tradition,[15] we must recognise—within decision-making—the ontological impact of being vulnerable, without this signifying that the ideals and feelings of the patient and their family may be subjugated with respect to the scientific-positivist-reductionist hegemony. In this context, as in many others, it is about establishing a more holistic phenomenology of the vulnerable person, considering who the person is, what they want, and negotiating with the principles that govern bioethics (principlism) to create a common agreement between them, seeking a balance centred on the patient's well-being.

Life cannot simply become a means to an end. People who are in a state of vulnerability are fragile and retain their humanity despite not realising this in a paradigmatic way, because they do not lose the meanings that link them or connect them with their family and society, or their moral status before the world.

The ability to make decisions based on the principle of autonomy is determined by the capacity and sufficiency of mental functions, so that each person can make decisions related to themselves and their environment. However, in multiple contexts, people may have limitations in their mental functions, such as dementia, which produces a type of hierarchy of people who have sufficient cognitive abilities over those who do not, and this generates fractures in their autonomy. Therefore, it is a duty to recognise the heteronomous nature of human relations, as well as the plurality of humans, especially in relation to their own body and the events that may occur in it. Faced with these challenges, we must understand the person with dementia "face-to-face", as Levinas suggests, in terms of their subjectivity, examining the vulnerability and the responsibility we have towards this person, in light of their limitations and seeking to guarantee their individuality and moral status. This position, based on *alterity*, seeks to understand what the patient wants, to understand the condition that is weakening their autonomy, and to enable relationships of recognition, and interventions concerning the person and their family, and to create an exchange in which visions of the world, certain values and concepts can be shared.[11]

Character and unexpected happiness

The value of autonomy reflects the person's ability to express their own character. Dworkin proposes a conception of autonomy centred on character, where there is a wholeness of the person's experiences according to their life, in which their narrative and coherence prevails, based mainly on their wants and desires. Therefore, although a person with dementia is significantly affected by his or her condition, general judgements about the type of life they would have liked to have led in the past should be considered, especially by their relatives and caregivers.[16] Therefore, the patient's family members and caregivers should promote their autonomy and integrity and look after their interests.

Every person has interests, which make life better if they are satisfied, and they are interests that, if not satisfied, would affect the person, in terms of them being an autonomous agent. Dworkin argues that the fulfilment of these interests is still in a person's best interest, even if the person would reap no experiential reward from it to argue in favour of their own life. In other words, critical interests, such as autonomy, prevail over external interests.[8]

Dworkin posits that there may be conflicts between the interests of the present or contemporary person with dementia over the same person without dementia in the past, seeking a balance between beneficence and autonomy. However, we may also consider that the autonomy can be "unravelled" by seeking the patient's best interest, and overriding the autonomy of the patient's past *self* under rare extenuating circumstances when the patient's present *self* finds an unexpected happiness.[17]

It is important to be attentive to the narrative of a patient with dementia, because dementia causes difficulties in articulating coherent and meaningful ideas. Therefore, care is essential in dementia, both for the patient and for the caregivers. In narrative care, people with dementia are treated not as impaired patients who are defined by the disease, but as human beings. In doing so, people with dementia can reclaim their own voices, which are so often silenced and discredited.[16,17]

Advance decision-making in people with dementia

As I have stated up to this point, decision-making is essential for a person's autonomy, especially when dealing with a person with dementia. If the diagnosis is early, it is advisable to inform the patient about their condition and promote the preparation of a living will, and even more so if their clini-

cal condition becomes critical to the point of reaching an end stage of the disease, in which their capacity for agency and autonomy are greatly weakened.

By assessing the decision-making capacity of a patient with dementia we can determine aspects whether the patient is able to give informed consent, participate in the research, manage their finances, live independently, plan for future health-related decisions, among others.[18,19] It cannot be assumed that patients with dementia lack decision-making capacity, and therefore this type of assessment is relevant. Even if they had an evident impairment of this capacity, their autonomous characteristics and capacity for agency would be present—even if at a very reduced degree—in order to express their understanding or select certain preferences. The functional assessment should include an assessment of the person's baseline cognitive status, and the assessments should be specific to the patient's particular situation, as they cannot have an overall scope.

These assessments are carried out with the patient and in the company of their family members and primary caregivers. It is also essential that the clinician be well informed and keep meticulous records. It is crucial to strike a balance between respecting the patient's autonomy and acting in their best interest.[19]

There is a tool, called MacArthur Competence Assessment Tools for Treatment, which is used to assess the validated competence of everyday decision-making in patients with dementia, and it is useful in helping to understand whether or not there is a functional deficit (for example, money management). It also makes it possible to assess the complexity of the problem, as well as the risks and benefits of solving it. The tool is based on a semi-structured interview that helps doctors to perform assessments of a patient's competence, autonomy and decision-making capacity to give their consent to a treatment. The process provides the patient with information about the medical or psychiatric condition that requires intervention, the type of treatment recommended, its risks and benefits, as well as other possible treatments and their likely consequences. During this process, the patient's understanding, appreciation and reasoning regarding treatment-related decisions are assessed.[20,21] Therefore, this scale makes it possible to assess how much knowledge the patient has about their condition and treatments, so as not to overload the caregivers with decision-making, and to preserve the patient's autonomy to consent or refuse treatments and to define a therapeutic ceiling, among other things.[22]

Understanding and integrating the importance of advance decisions helps us to safeguard and uphold the autonomy of a patient with dementia, serving as a guarantee for making the right decisions. Helping to ensure the safety of these patients through the implementation of theoretical and practical frameworks that recognise their limitations is a means of ensuring respect for their dignity, and for the value they have in society.

Conclusions

The increasing number of diagnosed cases of dementia means that we have to confront important and specifically ethical issues related to what it means to live a good life and the importance of being respected as a unique human being. To guarantee this, it is necessary to understand how a person with dementia is autonomous in terms of self-governance, and accept that they are people who can make choices based on their own thoughts, judgements and deliberations, never assuming that they do not have decision-making capacity without having carried out an exhaustive assessment or by taking a holistic, rigorous and empathetic approach.

Open and effective communication, good relationships with family members and caregivers, an appropriate approach to problems, and respect for people and their diversity, are the principles that should guide the care of patients with dementia. This is particularly important in a clinical setting, where there are significant gaps and asymmetries in relationships due to the different states of vulnerability of the people with dementia.

Despite having presented several arguments defending the recognition of autonomy in people with dementia, there are still a number of problems to be clarified, which indicates the need for further philosophical, medical and ethical analysis.

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