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Commentary

Ethical dilemma for healthcare professionals facing elderly dementia patients during the COVID-19 pandemic



Dilemme éthique pour les professionnels de la santé confrontés à des patients âgés atteints de démence pendant la pandémie de COVID-19

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ARTICLE INFO

Article history:

Received 8 April 2021

Accepted 13 September 2021

Available online 25 October 2021

Keywords:

COVID-19

Dementia

Shared decision making

Psychological safety

Ethics

Public health

ABSTRACT

The management of elderly patients with dementia and COVID-19 infections without access to an intensive care unit gives rise to serious ethical conflicts. Therapeutic decisions have been made in psychogeriatric units, leaving a heavy moral burden on staff. They had to deal with the most difficult patients without the support of appropriate guidelines. The gap between established rules and hospital reality led to psychological distress and burnout. Managing uncertainty in medical decisions is a skill that doctors and staff learn through experience. However, with the COVID-19 pandemic, uncertainty about patient outcomes seems no longer acceptable. Geriatric triage has challenged professional conscience, emotions and values. The principle of distributive justice, which consists of giving each person in society what is rightfully his or hers, is not being respected during this pandemic. Charity has been reduced to patient survival. Staffs need to make decisions together, and it is important to allow all carers access to a space for reflection. In our unit, the involvement of nurses and care assistants in the decision-making process for patient care is crucial especially for refusal of care. Their view of the patient's condition is different from that of the doctors, as they provide daily care to the patient and stay in the wards for several hours with them. By including as many people as possible in the reflection, we could avoid moral or personal prejudices related to these difficult decisions. The current pandemic can give new meaning to team thinking, giving everyone a voice without hierarchical barriers. With these new waves of COVID-19, we need to rethink our therapeutic conduct for elderly patients with dementia to avoid ethical failure.

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RÉSUMÉ

La prise en charge de patients âgés atteints de démence et souffrant d'infections à COVID-19, sans accès à une unité de soins intensifs, donne lieu à de graves conflits éthiques. Des décisions thérapeutiques ont été prises dans des unités psychogériatriques, laissant une lourde charge morale pour le personnel. Elles ont dû faire face aux patients les plus difficiles sans le soutien de directives appropriées. L'écart entre les règles établies et la réalité hospitalière a conduit le personnel à la détresse psychologique et au *burnout*. Gérer l'incertitude dans les décisions médicales est une compétence que les médecins et le personnel apprennent par l'expérience. Pourtant, avec la pandémie de COVID-19, l'incertitude sur le devenir du patient ne semble plus acceptable. Le tri en gériatrie a mis à rude épreuve la conscience professionnelle, les émotions et les valeurs de chacun. Le principe de justice distributive, qui consiste à donner à chaque personne dans la société ce qui lui revient de droit, n'est pas respecté durant cette pandémie. La bienfaisance a été réduite à la survie du patient. Le personnel a besoin d'élaborer ensemble des décisions et il est important de permettre l'accès à tous les soignants à un espace de réflexion. Dans notre service, l'intervention des infirmières et des aides-soignantes dans le processus de décision pour la prise en charge des patients est primordiale, notamment pour évaluer le refus de soin. En effet, leur vision de l'état du patient est différente de celle des médecins, puisqu'ils fournissent des soins quotidiens

Mots clés :

COVID-19

Prise de décision partagée

Sécurité psychologique

Éthique

Santé publique

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au patient et restent dans les unités pendant plusieurs heures avec eux. En incluant le plus grand nombre de personnes possible dans la réflexion, nous pourrions éviter les préjugés moraux ou personnels liés à ces décisions difficiles. La pandémie actuelle peut donner un nouveau sens à une réflexion d'équipe donnant à chacun une voix sans barrières hiérarchiques. Avec ces nouvelles vagues de COVID-19, nous devons repenser notre conduite thérapeutique pour les patients âgés atteints de démence afin d'éviter un échec éthique.

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1. Introduction

At the beginning of April 2021, there were more than 188 million confirmed COVID-19 cases worldwide, more than 4 million deaths [1] with a higher mortality rate in older people [2,3]. Elderly patients with major neurocognitive disorders are more vulnerable to lung diseases compared to other patients, with higher mortality [4] and they have more co-morbidities than other elderly patients on average [5]. Nonetheless, these patients rarely received invasive acute care [6]. Although there is no expert consensus nor dedicated recommendations focusing on this specific population, most practitioners were compelled to make a choice due to overburdened health care systems [2,7]. Given the overcrowding of intensive care units (ICU) in France at the height of the epidemic, age and dementia had to be discriminating criteria for admission. However, one can wonder whether this attitude led to a lack of chance for certain elderly patients [8]. That's why caring for older dementia patients suffering from COVID-19 infections without access to ICU lead to strong ethical conflicts.

Psychogeriatric units have to deal with the most challenging patients without the support of appropriate guidelines [7,8]. It seems useful to us to share the experience of this type of unit in this period of pandemic. Bretonneau psychogeriatric unit (Assistance Publique, Hôpitaux de Paris) was created in 2000 as a resource center for the region (8th, 17th, 18th boroughs of Paris) for patients over the age of 70. The team includes geriatricians, a neurologist, a psychiatrist, neuropsychologists, psychologists, social workers, nurses specifically trained in geriatric assessment, and several therapists specializing in physical therapy, ergo-therapy, art-therapy, and psychomotor therapy. The team meets weekly to discuss each patient's individual therapeutic project and to regulate the staff's own group dynamics.

Indeed, psychogeriatric staff found itself questioning its own ethical rules in this pandemic period. At the end of the day, therapeutic decisions were made in each psychogeriatric unit, leaving a heavy moral burden for staffs. The gap between the established rules and the hospital reality could lead staff to psychological distress and burnout.

2. Major ethical issues that teams are facing in this pandemic

Usually, patients' autonomy [9] needs to be respected to preserve their ability to return home. However, often dementia patients with COVID-19 developed behavioural disturbances with agitation and delirium. Staffs must limit patient wandering to allow for care, especially oxygen therapy, and also to prevent the spread of the virus in the unit [10]. However, some dementia patients cannot understand the provided care. The risk-benefit ratio of this deprivation of liberty only makes sense if the proposed care protocol could bring an improvement for the patient, but sometimes the lack of therapeutic perspectives makes this decision uncomfortable for all staffs as it is well known that upper limb and abdominal restraint risk of aggravating delirium [11].

There was no general rule in the department concerning the restraint of ambulating patients. Each case was treated individually according to the patient's health status, the care provided, the level of viral replication and the duration of the symptoms. A viral replication level greater than 33 in a patient more than 14 days into the course of COVID infection allowed free ambulation. Even patients who did not have these criteria but were restrained in the room were decontaminated every day at different times so that they did not cross each other and were allowed to wander around the unit under the supervision of a nurse wearing a surgical mask. This allowed us to reduce the agitation of certain patients who could not stand the restraint and whose behavioral problems were getting worse, sometimes with a feeling of persecution. We tried to find a compromise between the individual freedom of each patient and the risk of contamination of healthy patients in the department.

This leads us to question the patient's ability to decide and refuse care. Some physicians think that this refusal should be respected in the name of the person's autonomy, while others argue that one's values are altered by delirium and cognitive disorders and do not enable the patient to decide on treatment or refuse care. Some physicians believe that this refusal should be respected in the name of the person's autonomy, while others argue that the person's values are impaired by delirium and cognitive impairment and do not allow the patient to decide on treatment. Indeed, assessing the patient's ability to decide on treatment, for example with the MacCAT test requires stable neurological and psychiatric status [12]. Although the presence of neurocognitive disorders is not synonymous with an inability to decide [13], delirium is considered an impediment to a reliable decision. Unfortunately, our patients with dementia often had not written advance medical directives or identified a trusted person before the onset of their disorder. Moreover, unlike other decisions, the decision to treat a life threatening condition cannot be postponed until the neuropsychiatric condition is stabilized. This has led us on several occasions to make decisions about whether or not to continue curative management for patients whose condition was not improving. Indeed, some patients with dementia are not able to express their wishes regarding medical decisions.

Then, if the patient's condition does not improve, the physicians face a dilemma. Elderly demented patients with multiple co-morbidities are not eligible for ICU, but initiating palliative care could be a particularly tough decision to make. On the one hand, the principle of justice [9] must allow all patients to equally access effective care but, on the other hand, there are concerns of unreasonable obstinacy and aggressive treatment for patients who had little chance of recovery.

3. Shared decision making for elderly dementia patients during COVID-19 pandemic

In these situations, it appeared that the values of physicians and nurses are of high importance in the decision-making process [14]. Although the patient's values must be taken into account as much as possible according to his mental status, the values of nurses need

to be individually considered, and confronted to each other in this process to allow mutuality and a global consensus. The response to the COVID-19 pandemic forced all healthcare workers at all levels to reflect further on their practice and ethics. The lack of a clear care protocol has strained everyone on their professional conscience, their emotions and their values. At the forefront, the nurses and nursing assistants' intervention in the decision-making process for the patient's management and outcome are also of interest. Indeed, their view of the patient's condition is different from that of the physicians, as they provide daily care for the patient and stay in the units for several hours with them. They could also understand non-verbal communication. Moreover, it has been shown that for certain types of care, the greater the number of carers, the less medical errors there are with elderly demented patients [15]. In intensive care units too, it has been shown that nurses have different perceptions from physicians regarding invasive treatments and patients' intubating decisions [16]. In our unit, their views regarding patient refusal of care were paramount. Indeed, the time spent with the patients allowed them to know well the different reactions of the patients to the different care and to be able to distinguish between a voluntary refusal of care and a refusal of care linked to a lack of understanding. This has helped us a lot in our multidisciplinary discussions to decide whether or not to continue curative care in worsening conditions.

In the absence of an ethical review, it is essential to consider each patient on a case-by-case basis. Tools to assess the value of treatments for the elderly during the COVID-19 pandemic have been published [8] but by only following a process or codes of conduct, one cannot avoid ethical failure. Moreover, since the beginning of COVID-19 pandemic, all people and particularly health workers are vulnerable to psychological distress and burnout. Their lives were dramatically affected with anxiety, sadness and fatigue [19]. Their decision-making is challenged at every level. This is especially true for decisions involving ethical dilemmas or when the meaning of care is lost. By including as many people as possible in the reflection, we could avoid moral or personal biases that may affect the perception of decisions made for patients. Staff need to develop decisions together and it is important to provide a space for reflection for all. By improving the experience of nurses, we can improve practices by restoring care's meaning and thus allow for better quality of care even when it is no longer for curative purposes.

4. Ethical versus financial considerations: thinking about the limits

One should emphasize that in France, all people have the same access to care independently of financial limitations. This situation created an intergenerational conflict with suspicion of ageism [17] on the part of the younger population. The principle of survival outweighed the principle of justice favouring patients with the best chances to survive in good health after intensive care [18]. Dealing with uncertainty in medical decisions is a skill that physicians and staffs learn through experience. With the COVID-19 pandemic, the uncertainty is no longer acceptable. In fact, due to the lack of place in intensive care, it seems unreasonable to transfer to these units patients for whom the probability of recovery is poor. It is sometimes decided to "sort" the patients in advance and decide which ones could go to intensive care if their conditions worsen and which could not. Our patients with major neurocognitive disorders are usually admitted to the ICU only if their general condition is considered good and their quality of life remains good with good autonomy. During this pandemic, the requirement of resuscitators to allow these patients to benefit from resuscitation was greater due to a lack of space for all patients. The staff responsibility should not, according to their own criteria, compensate for a lack of means

at the national level. This leads to shifting the moral responsibility for a vital decision onto physicians when it is more of an economic and societal problem.

The principle of distributive justice [9], which means giving each person in society what is rightfully his or hers, is not respected during this pandemic. The distribution of health goods is thus crossed by a tension between utilitarianism and egalitarianism, which means that the interest of the greatest number is privileged rather than treating everyone fairly. As a result, we often refused in principle to hospitalize in intensive care patients over 75 years of age according to the hypothesis of keeping beds for the youngest who, due to comorbidities, would not have survived the intensive care unit. Beneficence [9] was reduced to the survival of the patient.

Multidisciplinary meetings in the department helped us to accept this health situation and the choices that were made for our patients.

Although organizational and leadership practice remain a necessity, the current COVID-19 pandemic gave a new meaning to a team reflection giving everyone a voice without hierarchical barriers. With these new waves of COVID-19, we need to rethink our therapeutic conduct for elderly dementia patients to avoid ethical failure.

Ethical standard statement

No.

Consent to participate (include appropriate statements)

Not applicable.

Consent for publication

All authors consent to the publication of the manuscript.

Availability of data and material (data transparency)

Not applicable.

Code availability (software application or custom code)

Not applicable.

Funding

This article received no funding.

Authors' contributions

Mouna Romdhani is the main author, the patient's physician and she wrote the paper with support from Samuel Kohler, Pierre Koskas and Olivier Drunat.

Disclosure of interest

The authors declare that they have no competing interest.

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