
Ethical dilemmas for nursing home doctors during the COVID-19 pandemic

ORIGINAL ARTICLE

EMILY MCLEAN

emily.mclean@uib.no

Bergen Centre for Ethics and Priority Setting (BCEPS)
Department of Global Public Health and Primary Care
University of Bergen

Author contribution: idea formulation, study design, data collection, data analysis, literature search, lead responsibility for preparation and revision of the manuscript, and approval of the submitted version.

Emily McLean, doctor and PhD research fellow.

The author has completed the ICMJE form and declares no conflicts of interest.

KRISTINE HUSØY ONARHEIM

Bergen Centre for Ethics and Priority Setting (BCEPS)
Department of Global Public Health and Primary Care
University of Bergen

Author contribution: idea formulation, study design, literature search, preparation and revision of the manuscript, and approval of the submitted version.

Kristine Husøy Onarheim PhD, doctor and affiliated researcher.

The author has completed the ICMJE form and declares no conflicts of interest.

ELISABETH SCHANCHE

Department of Clinical Psychology
University of Bergen

Author contribution: idea formulation, literature search, preparation and revision of the manuscript, and approval of the submitted version.

Elisabeth Schanche, professor of clinical psychology.

The author has completed the ICMJE form and declares no conflicts of interest.

MARGRETHE AASE SCHAUFEL

Department of Pulmonary Disease
Haukeland University Hospital
and
Department of Clinical Medicine
University of Bergen

Author contribution: literature search, preparation and revision of the manuscript, and approval of the submitted version.

Margrethe Aase Schaufel, specialist in cardiopulmonary diseases, senior consultant and associate professor.

The author has completed the ICMJE form and declares no conflicts of interest.

INGRID MILJETEIG

Bergen Centre for Ethics and Priority Setting (BCEPS)
Department of Global Public Health and Primary Care
University of Bergen
and

Department of Research and Development
Helse Bergen Health Trust

Author contribution: idea formulation, study design, data analysis, literature search, preparation and revision of the manuscript, and approval of the submitted version.

Ingrid Miljeteig, professor of medical ethics and deputy director of BCEPS. She is the chair of the clinical ethics committee at Haukeland university hospital.

The author has completed the ICMJE form and declares no conflicts of interest.

BACKGROUND

Nursing home residents were particularly vulnerable to a serious clinical course of COVID-19. It was therefore decided early in the pandemic that nursing homes needed to be protected through measures such as testing and isolation regimens and restrictions on visiting. This entailed new procedures and guidelines for nursing home doctors. Norwegian and international studies show that the pandemic presented new ethical dilemmas for healthcare staff. The aim of this study was to provide a better understanding of the ethical issues faced by nursing home doctors during the pandemic.

MATERIAL AND METHOD

Nine semi-structured in-depth interviews with doctors at five nursing homes in Bergen were analysed using Attride-Stirling's thematic network analysis.

RESULTS

The doctors told of challenges related to deciding the level of treatment, setting limits for palliative care, adapting visiting restrictions, and assessing the use of coercion with regard to testing and isolation. This entailed difficult ethical considerations whereby doctors were faced with conflicts of interest and value judgements, central to which was consideration for the individual resident versus society.

INTERPRETATION

The nursing home doctors in our study found it difficult to find a balance between protecting the residents' autonomy and preventing the spread of infection.

Main findings

Determining the level of treatment and providing adequate palliative care in the end-of-life phase posed challenges.

Enforcement of visiting restrictions led to ethical dilemmas, particularly as regards care of dying, cancer and stroke patients.

Use of coercion in testing and isolation to stop the spread of infection had to be weighed up against consideration for the autonomy of the residents.

A central dilemma was the interests of the individual resident versus the interests of the community.

Almost half of the COVID-19 deaths in Europe from the start of the pandemic until January 2021 occurred in nursing homes (1). In Norway, the majority of COVID-19 deaths in 2020 were in the over-80s, and many of these people died in nursing homes (2). Norwegian nursing home residents have an average age of 84 years, a high burden of disease, and 8 out of 10 have dementia (3, 4). These factors increase their vulnerability to a serious clinical course of COVID-19. Early in the pandemic, it was decided that nursing home residents had to be protected through measures such as restrictions on visits from relatives, testing regimes and isolation of suspected cases (5).

The COVID-19 pandemic led to changes in procedures and the workload of healthcare staff in nursing homes. New routines and guidelines were introduced in a short space of time and required rapid reorganisation. At the start of the pandemic, there were particular challenges related to a lack of staff, personal protective equipment and testing capacity (5). There were also large differences between the nursing homes in terms of the numbers of COVID-19 patients. Some had dealt with large outbreaks and many deaths, while others had not (5).

The Norwegian Coronavirus Commission's report concluded that, despite the heavy burden, nursing homes received too little attention during the pandemic compared to the specialist healthcare service (6). Studies from various countries show that healthcare staff who worked during the pandemic, both in nursing homes and other areas of the healthcare sector, experienced various ethical and prioritisation dilemmas (7–9).

The aim of this article was to describe the ethical challenges experienced by nursing home doctors during the COVID-19 pandemic in Bergen and the assessments they made. This is important to gain a better understanding of the measures taken during the pandemic and may provide useful knowledge about preparedness in case of future disease outbreak.

Material and method

The article is based on a qualitative analysis of nine semi-structured individual in-depth interviews with nursing home doctors who worked during the COVID-19 pandemic at five different nursing homes in Bergen. Bergen was chosen due to the high infection rate early in the pandemic, which led to several rounds of strict local guidelines. Data collection took place from June to September 2021.

The study is part of a larger COVID-19 study in the Western Norway Regional Health Authority (approved by the Western Regional Committee for Medical and Health Research Ethics 'REK Vest' (131421)). All the managers at nursing homes in Bergen municipality were invited to participate in one part of the study. Doctors at the nursing homes who expressed an interest in taking part were contacted by email (19 doctors in total). We included doctors who were working in the period from autumn 2020 to summer 2021. Some had dealt with major outbreaks and deaths, others had experienced these to a lesser extent or not at all. Further recruitment into the study took place through snowballing.

The interview guide focused on questions about ethical challenges experienced generally during the COVID-19 pandemic, with specific questions about hospitalisation, visits and infection control measures (see appendix). The interviews lasted 30–50 minutes. The data material was analysed using Attride-Stirling's thematic network analysis, a systematic process for identifying and organising the overall themes in the material (10). The material was first reviewed then coded. The codes were collected under themes that best described them. The themes were then grouped into organising themes, which made up the five main ethical dilemmas presented in the results section.

The analysis tool Nvivo was used for data management (11). All the participants gave written consent to participate. Due to the limited number of nursing home doctors in Bergen municipality, we decided not to provide information about the nursing home doctors' place of work, gender or professional experience to safeguard anonymity.

Results

At the start of the pandemic, there were great fears about COVID-19 outbreaks in nursing homes. Several doctors reported that they had to work longer days than normal, and isolated themselves from their family and friends due to fears of bringing infection into the nursing home. The period was described as a frightening time, but also a time when solidarity among colleagues was strengthened through the collective effort to fight the pandemic.

Some nursing home doctors dealt with major outbreaks and many deaths, while others did not. Nevertheless, the pandemic led to drastic changes in the normal working day, with new routines and regulations that the nursing home doctors had to interpret and enforce daily. The study identified five main ethical dilemmas experienced by the nursing home doctors during the COVID-19 pandemic. These involved assessments

related to decision-making about the level of treatment and when to restrict treatment, setting limits for end-of-life palliative care, adapting visiting restrictions, defining when a patient was dying, and use of coercion with regard to isolation and testing.

What level of treatment to choose?

Deciding what level of treatment the nursing home resident should receive and what medical action should be taken was ethically challenging.

"Issues that had long been a focus in nursing home medicine became magnified during the pandemic. (...) Should a 90-year old multimorbid nursing home patient go to intensive care and take up an intensive care bed? What would this patient gain from being admitted to hospital?" (interview #1)

Several mentioned that this was particularly notable in the first phase of the pandemic when there was less knowledge about the transmission routes of the virus and the effectiveness of infection control measures. In addition, there was much uncertainty related to hospital capacity and concern about overloading the specialist healthcare service. National prioritisation guidelines clearly stated that unnecessary admissions to hospital had to be avoided. This created a sense that the threshold for admission was higher than usual, and it became harder for nursing home doctors to make the assessment.

"The [residents] who were candidates for investigations, we felt they were slightly sidelined. Also bear in mind that we often received clear messaging from the hospital that things had to be postponed, it's not so urgent now, we need to wait." (interview #8)

Where is the limit for palliative care?

Several of the nursing home doctors that experienced COVID-19 deaths spoke of difficulties related to providing good end-of-life palliative care. It was known early on that patients dying from COVID-19 could experience a sense of suffocation at the end-of-life. This was a new experience that required nursing home doctors to adjust the treatment, and some found that it was necessary to give larger doses of morphine for adequate palliative care in end-of-life COVID-19 patients.

"We have learnt that sometimes the standard palliative doses need to be increased. The fact that we focus on, 'OK, if we don't achieve the goal here, you are allowed to insert a venflon and give it intravenously', so maybe our approach has become a bit more dynamic." (interview #1)

Several doctors reported concern that residents dying of COVID-19 might experience suffering, and they wanted to provide the best palliative care possible. Since the doses of morphine had to be increased to provide adequate relief, this created an ethical dilemma about the boundary between relieving suffering and active assisted dying.

"In these cases we gave much larger doses [of morphine] straight away. In that sense, we were more weighing up in a way taking someone's life against them suffering, it was more like maybe we were not as afraid about them dying from it (...) I am not in favour of euthanasia (...), but I really want to help alleviate suffering. And so alleviating suffering became so important here because we thought that it might be a really awful death. Therefore, we were less afraid of taking life." (interview #9)

When can relatives come?

The visiting restrictions resulted in relatives not being allowed to visit their loved ones in nursing homes unless they were dying. Some of the nursing home doctors in the study were not involved in enforcing the visiting restrictions, and thus they did not feel that there were ethical challenges in that respect. At other nursing homes, it was common to involve the doctor in these decisions, and several doctors found it very challenging to interpret how to best enforce the visiting rules.

"When should you say that it is alright for relatives to come anyway? The consequence of an outbreak in a nursing home, at any rate before the nursing home patients had been vaccinated, was pretty serious." (interview #7)

The doctors were keenly aware that the restriction on visitors to the nursing homes caused a reduction in the activities on offer and daily contact with relatives, and that this had adverse consequences for the health of many of the nursing home residents. Whether to follow everything that was allowed or not allowed in accordance with local guidelines was a difficult balancing act. Several doctors pointed out that they had a 'pragmatic' approach to the rules about no visits, and that they made adjustments based on the residents' needs and made their own assessments about the situations.

"You have to comply with the guidelines, but you also have to be brave enough to deviate from them. Individual assessments meant that there have been vast differences in practice." (interview #6)

When is the patient dying?

Exemptions to the visiting restrictions were granted for residents who were dying, and so it became important to define when someone was dying. However, it was not always that straightforward because the residents were usually elderly people whose remaining life expectancy was short in the first place. Several of the nursing home doctors expressed that they wanted relatives to be able to visit their loved ones while they were still aware and could appreciate the visit, but it was difficult to define this. Particular challenges arose with assessments regarding cancer patients receiving palliative follow-up at the nursing home and young stroke patients with small children. Where to set the limit about when they should receive visits?

"If the cancer patient is severely ill, but might live for a couple more weeks, is the patient dying then? It was impossible to draw a line, and these are difficult decisions in the first place." (interview #4)

This was further illustrated by the story of an elderly resident who was not dying, but who it was expected might die of old age relatively soon. It was difficult to weigh up allowing the resident to have visits, which would be unfair on the other residents who did not have visits, against the fact that the resident was very old with a short remaining life expectancy.

"[The resident] was very old and had a relatively short remaining life expectancy. [The resident] was not exactly terminally ill, in which case it would have been simple to allow visits, that's not an issue, but technically [the resident] might die at any time [because the resident was so old]." (interview #1)

When can coercion be used?

Testing and isolation were important to prevent the spread of COVID-19 in the nursing homes, but caused ethical dilemmas. The measures could be challenging to implement in practice, especially in the case of residents with dementia where it was difficult to explain what they had to do and why. In Bergen municipality, testing and isolating with coercion was allowed if necessary. The doctors reported that coercion was rarely used, but that it was ethically challenging to balance compliance with mandatory testing and isolation for several days against the resident's autonomy.

"When conducting testing, people can be released (...) otherwise they have to be isolated for a very long time. So most people were tested, but I don't know whether it was right, because a large number will say 'yes' [to testing] when you ask, but it is not certain that they understand what they are answering. So the swab goes up their nose, which can be done quite quickly, but it does hurt." (interview #9)

Residents that wander were challenging to isolate, and so cohort isolation was implemented at several nursing homes. A central isolation department was also set up where residents with confirmed infection could be transferred. In the cohorts, infected residents could move around freely while staff wore personal protective equipment. This was seen by several doctors as a midway solution that was less restrictive on the residents' freedom of movement, and also made it possible to both consider what was best for the patient and to protect staff and other patients from infection.

"It is obvious that what is best for the common good is not always best for the patient. When quarantine is imposed and a patient with cognitive impairment has to be isolated, this is not in the patient's best interests. It is what is best for the community." (interview #7)

Discussion

We found that the extraordinary situation created by the pandemic resulted in challenging ethical considerations for the nursing home doctors. The central ethical issue was consideration for the individual resident versus the community, which meant the doctors faced challenging conflicts of interest and value judgements.

How to allocate resources fairly?

Several of the participants in the study thought that the pandemic had magnified already difficult decisions about the hospitalisation of nursing home residents. At the start of the pandemic, the nursing home doctors found that they often had sole responsibility for the residents and that residents requiring investigations were de-prioritised to ensure that hospitals had capacity.

A study of ethical dilemmas in Norwegian hospitals during the pandemic concluded that healthcare provision to the elderly was probably not good enough at the start of the pandemic (12). Others have also criticised the prioritisation guidelines for indirectly leading to age discrimination, which in turn led to a disproportionately low hospitalisation of nursing home residents during the pandemic in Norway (13, 14). Relatives have also expressed concern regarding explanations about treatment and felt that they were not properly informed during the processes (5, 14).

There are few international empirical studies researching the experiences of doctors in the prioritisation of hospitalisation of nursing home residents during the pandemic, but in one study among nurses in Sweden several people described experiencing elderly patients not being allowed to go to hospital when they needed to (15).

Although hospitalisation from nursing homes in normal non-pandemic times usually involves weighing up what is good for the patient against what might cause more harm, consideration for the principle of fair allocation of resources was highlighted by the pandemic. In addition, the individual doctor's autonomy in decisions about hospitalisation was perceived to be restricted by guidelines or signals from the hospitals at the start of the pandemic. At the same time as the burden on the specialist health service was supposed to be lessened, the nursing home doctors also acquired an entirely new role related to limiting the spread of infection inside nursing homes and between residents.

The price of limiting infection

The visiting restrictions have been difficult for many residents in nursing homes. Numerous residents were isolated from their loved ones, and the provision of activities was temporarily suspended, resulting in increased depression and loneliness (16). Our findings show that several nursing home doctors found it difficult to enforce the strict visiting rules and decide where to draw the line. These ethically challenging assessments were in line with findings from other Norwegian nursing homes (5). The balance between preventing infection, ensuring the residents have a life worth living, and facing pressure from relatives to allow visits resulted in burn-out and difficult ethical dilemmas, also in nursing homes outside Norway (5, 8, 9).

The emotional burden of having to choose between physical protection from COVID-19 and the residents' need for contact with their families is supported by findings that show the importance of social contact with people we are connected to. Loneliness and social isolation among the elderly affect their well-being and quality of life, as well as causing impaired cognitive function, depression, suicidality and increased mortality (17–19). Therefore, the nursing home doctors faced situations in which they had to balance different considerations to ensure the residents' health and survival.

This also applied to the use of coercion with the testing and isolation of residents, particularly those with dementia. Use of coercion is one of the most powerful measures in medical practice and healthcare establishments. Being able to carry out a treatment even if the patient opposes it challenges the principle of autonomy, and therefore the healthcare professional, other staff and the patient can find it challenging. Nursing home staff may feel guilty and inadequate when they use coercion, even if its use is seen as the last resort (20). Doctors at other nursing homes in Norway have also experienced ethical dilemmas surrounding the use of coercion during the pandemic (5). A group of English researchers studied ethical and legal aspects of using coercion when isolating patients with dementia during the pandemic, and they recommend allowing ethical considerations to determine the need for use of coercion on a case-by-case basis instead of having one rule for all (21).

Deciding when someone is dying?

Visiting restrictions for relatives impacted all the residents, with the exception of those defined as dying. However, there is no single definition in medicine of when a patient is dying, and the definitions range from hours to months before the expected death (22, 23). The doctors described difficult ethical assessments related to residents with a short remaining life expectancy, particularly patients with cancer admitted for palliative follow-up and young stroke patients.

It is difficult to predict when elderly patients are dying, especially patients with dementia, because their daily condition often fluctuates (24, 25). Furthermore, deaths due to COVID-19 took a more rapid course than 'normal' deaths in nursing homes, which meant that decisions had to be made quickly (26). In the Netherlands, nursing home doctors reported that the grey area between the preterminal and the dying phase meant that several nursing home residents were alone in the last stage of their life during the COVID-19 pandemic (8). At the same time, there was a high risk of bringing infection into the nursing home if the definition of someone dying was set too early. Therefore, there was a conflict between giving good care in the end-of-life phase – for both COVID-19 patients and other patients – and preventing multiple residents from becoming infected (5, 8).

Another dilemma that arose in caring for end-of-life COVID-19 patients was that many needed larger doses of morphine to provide adequate relief. One participant in the study expressed concern as to whether the high doses were approaching active assisted dying. Later in the pandemic, clearer guidelines were issued about how to give good palliative treatment to dying COVID-19 patients (27).

Strengths and weaknesses

National regulations and recommendations were the same for all nursing homes in Norway during the pandemic, even though infection rates differed. Municipalities did have local adjustments to regulations implemented based on infection rates, and this may have affected the types of ethical challenges experienced by the doctors in the study. The study sample was narrow, and therefore the ethical dilemmas described in this study cannot necessarily be generalised.

Nevertheless, the findings may be relevant to practice and discussions in other nursing homes and sectors of the health service that interface with nursing homes.

The qualitative method with individual interviews gave the opportunity to explore perceptions and experiences in depth that might otherwise be difficult to capture with quantitative methods (10). There is reason to believe that the ethical challenges changed during the pandemic as new guidelines were implemented. Therefore, there is a need for more studies into the ethical dilemmas and interactions experienced by doctors, management and other healthcare staff during the pandemic.

What can we learn?

The pandemic showed us that major restrictive measures affecting society pit the best interests of the individual against the best interests of the community. In the nursing homes in our study, the doctors had to weigh up the residents' autonomy against the risk of spreading infection. Several of the doctors felt that they had to bear a great deal of responsibility on their own at the start of the pandemic. This balancing act has been

challenging and must be recognised in further discussions about measures and restrictions in nursing homes, and in planning for future preparedness. While infection control is important, it is essential that there is space for clinical and ethical judgement, particularly in the end-of-life phase.

It is important to listen to relatives, residents and nursing home staff in the processes surrounding prioritisation criteria and restrictions in nursing homes in the event of future outbreaks. We can then reflect collectively on what is a life worth living for nursing home residents and what is a good end-of-life.

The article has been peer-reviewed.

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