Ethical Issues in Palliative Care

A Shot at Inclusion: Reconsidering Categorical Exclusion of Hospice Patients from COVID Vaccine Allocation

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Key Words

COVID-19, vaccination, immunization, hospice, palliative care, ethics

Introduction

The COVID vaccine offers the possibility of reducing morbidity and mortality from the coronavirus SARS-CoV-2 and hastening the end of the COVID-19 pandemic. In December of 2020, the Food and Drug Administration granted an Emergency Use Authorization for the Pfizer-BioNTech and Moderna coronavirus vaccines then with approvals in February for additional Janssen single-dose vaccines.[1,2] Several governmental public health and academic institutions have produced ethical frameworks for the allocation of the COVID-19 vaccine.[3–6] Though the ethical principles are weighed differently, all of these expert reports emphasize that utility and beneficence must be balanced with considerations of equity, fairness, and transparency. This case describes the need for palliative care and hospice clinicians to make decisions about COVID-19 vaccine allocation in their own practice based on the core values of these evidence-based frameworks rather than upon implicit bias or personal preferences for vaccine prioritization. The ethics team analyses approach included obtaining and clarifying the medical facts, identifying perspectives of the relevant parties, defining the values conflict, gathering authoritative guidance such as public health policy and vaccine allocation frameworks, identifying the ethically appropriate decision-maker, synthesizing considerations including culture and care model contexts, and thoughtfully deliberating among the range of ethically justifiable options and recommending the ethically preferable one. The ethical analysis of the case presented here supports vaccine prioritization policies and patient-centered communication, as means of identifying and resolving ethical problems that arise when a policy or practice is proposed that categorically withholds COVID-19 vaccination from patients on hospice.

Example Case Description

Ms. B is a 68-year-old Hispanic female resident of a nursing home that accepts patients on hospice care for inpatient services. She has a diagnosis of advanced pancreatic cancer with distant metastasis with a survival prognosis of likely six months to possibly one year. Until two months ago, Ms. B who is recently widowed, resided in her own home. After complications from disease-directed chemotherapy when she progressed to needing hands-on help with medication administration and nutrition, she decided to enter the nursing home. She is receiving visits from occupational and physical therapy and making slow but steady progress toward being able to perform activities of daily living. She is pleased with her new living arrangement and has decided to forgo additional chemotherapy to focus on quality of life and symptom management. Her advance directive reflects her focus on supportive care as does her do-not-resuscitate status. Ms. B recognizes her current frailty and the ultimately terminal nature of her oncologic diagnosis, while also hoping to regain the

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strength to return home with hospice support in the coming weeks.

There was a two-week delay in receipt of the vaccination supply and fewer vaccines shipped to the nursing home than anticipated. Staff worry about reliable vaccine supply for current and incoming nursing home residents.

Ms. B has expressed an interest in receiving a COVID vaccination as it is congruent with her primary goals of care to return home and focus on quality of life in her remaining months. She also believes the vaccine would protect the nursing home and hospice workers who care for her as well as enabling her to more safely visit with family members. As a registered nurse, Ms. B sees the authorization of the COVID vaccine as a historic moment in public health and a way to help protect fellow residents. Having worked as a school and parish nurse for many years, she is aware that many in her Hispanic community experience vaccine hesitancy and believes she can serve as a role model for vaccination.

Ms. B's son, a high school science teacher, learned from families of other patients in the nursing home that the vaccine was administered to other residents. He is upset to learn that his mother has not yet received the COVID vaccine despite her residing in a congregate living situation and having a diagnosis that compromises her immune system. He feels his mother should have already received the vaccination based on her medical risk as well. Ms. B's son meets with the hospice nurse to express his frustration that his mother has not yet been vaccinated and tells her this delay is just one more instance of the disparity in care his family has encountered since enrolling on hospice. He cites other examples of cultural insensitivity care: no availability of Spanish interpreters when older family members call for updates on Ms. B and an inability of the nutrition staff to accommodate Ms. B's traditional food preferences. The hospice nurse listens empathically to the son and promises to bring his concern to the medical director right away.

The nursing home medical director (who also serves as the hospice medical director) tells the nurse that he is worried about whether the nursing home facility will have enough vaccines for their current residents and pending admissions. There are not many vaccine doses available and he is concerned about possible vaccine shortage. He states that their philosophy of hospice care is that it is focused on comfort more than a preventive care model. It is his medical opinion that responsible stewardship of limited supplies of the vaccine would make the vaccination of patients with a life expectancy of six months or less a lower priority. He endorses a "fair innings" allocation strategy that would prioritize younger, healthier patients.[7,8] "Fair innings" implies prioritizing healthier patients who have not had the same opportunity to live through all life stages. The medical director tells the nurse the public health objective of the COVID vaccination is to save the lives of younger or healthier people who can then contribute to and enjoy economic and social recovery: a patient on hospice would be less likely to receive these benefits. The medical director emphasizes his belief that vaccine administration should be prioritized according to the number of life-years saved.

Ms. B's hospice nurse disagrees with the medical director's sentiment that patients enrolled on hospice should categorically be disqualified from receiving the vaccine. The hospice nurse recognizes that vaccinating Ms. B can protect the patient, the hospice team, and other patients in the hospice. The hospice nurse views offering the COVID vaccine as an integral part of quality hospice care that is also in accordance with Ms. B's preferences and goals of care. She believes offering the vaccine to inpatient hospice patients follows allocation guidelines which to her knowledge do not exclude patients solely on the basis of their hospice status.

Defining Issues

Each of the parties in this case has made a decision about the ethical justification of Ms. B receiving a COVID vaccination that reflects and incorporates their core values and personal health care preferences as well as their views about who should be prioritized. Ms. B prioritizes quality of life and disease prevention; her son prioritizes health care equity, reciprocity, and respect; her hospice nurse prioritizes individual dignity, equal concern, reciprocity toward health care workers, and other hospice patients; while the medical director prioritizes utility in the setting of uncertain supply, and maximizing benefit.

Ethics Analysis

Current Situation. Communication from hospice organizations has primarily emphasized the vaccination of hospice staff without the same priority mention for patients enrolled on hospice.[9,10] The National Association for Home Care & Hospice Resolution on the COVID-19 Vaccine emphasizes the urgency of vaccination access for hospice staff as well as "encourage and support the availability and administration of COVID vaccines to their patients and caregivers in the home."[11] Lack of collective or clear direction on vaccination for hospice patients leaves individual practitioners or facility leaders to make ad-hoc decisions about how to prioritize patients in hospice for the COVID-19 vaccine. Such decisions are more open to implicit bias and imposition of personal value judgments as this case shows. Recent ethics consults and content analyses of professional hospice listservs reveals thematic concerns: whether hospices can accommodate indirect vaccine costs such as purchase of cold storage units at a time of hospice budget stretch, whether a vaccine should fall within a hospice patient's goals of care, whether vaccination of hospice patients best supports community life-years saved, and whether preventive care falls within the purview of hospice care.

Allocation Framework. The Centers for Disease Control Advisory Committee on Immunization Practices (ACIP), the World Health Organization (WHO), and the National Academies of Sciences (NAS) prioritized residents of long-term care facilities and other congregate living settings in the first tier for receipt of the COVID vaccine in order to decrease transmission of the infection and cases of severe disease and death.[3–6] These documents do not mention patients in hospice per se. Unlike some scarce resource allocation plans and triage protocols for crisis standards of care,[12–14] these vaccine allocation frameworks do not consider life expectancy or life-limiting illnesses as exclusionary criteria for vaccines. Vaccine distribution guidelines and frameworks do not categorically exclude patients receiving hospice care but instead focus on the vaccination of vulnerable residents of skilled nursing and long-term care facilities. As a resident of a hospice housed in a nursing home, Ms. B is prioritized within the first patient group to be offered the COVID vaccine according to the national ACIP and NAS frameworks. Vaccine allocation frameworks with the goal of maximizing life-years saved would likely argue against prioritizing a patient on hospice.[14–16] The vaccine allocation process should follow evidence-based, equitable allocation frameworks in distribution vaccines.[3,17,18] Allowing authoritative guidelines to inform distribution fosters a fair, transparent approach and precludes decisions about vaccine prioritization based on the implicit bias or value judgments of individual practitioners.[19,20]

Patient Preference. Given that Ms. B meets the first-tier criteria for allocation, she is the ethically appropriate decision-maker regarding whether-or not she wishes to be vaccinated. Her decision reflects not just her own desire to be protected from COVID infection but also a wish to participate in the larger public health goal of reducing viral transmission and protecting other elder and frail residents of the unit and their caring staff.[21] Ms. B is not imminently dying but she is immune-suppressed and so she has a higher risk of developing severe disease and of dying from the virus if infected. Although Ms. B is not actively serving in a nursing role, her personal identity as a member of the nursing profession provides her with unique appreciation of the way the COVID vaccine development represents a remarkable scientific advancement and she wishes to be included in this landmark medical development.

Medical Director Perspective. The medical director recognizes that COVID continues to spread in his community. COVID-19 has been an extraordinary strain on his staff, residents, and budget He is now concerned that the much-anticipated vaccine will be in short supply or even unavailable as he tries to balance nursing home resident demand and actual supply, especially if new residents arrive. The medical director considers the vaccine a scarce resource and so he recognizes a duty to extend and maximize its benefits. His personal philosophy of care is to try always to treat people equally and promote respect for those most vulnerable. He believes he should give priority to patients who are more likely to survive longest so that those patients receive the most benefit in terms of time and sustained health. Operationally, maximizing benefits of the vaccine means first immunizing residents who could recover and sustain not just a subjective high quality of life but also a long-life expectancy after vaccination.

Equity and Inclusion. Some ethicists have argued that historic and current inequities in health care, as well as the greater burden of disease and death communities of color have suffered, warrants prioritization of these disproportionately burdened cohorts COVID in vaccine allocation plans.[22] Other ethical guidance, including ACIP and NAM, have recommended indirectly addressing these disparities through prioritizing essential workers and people with comorbidities like diabetes and hypertension which are epidemiologically more prevalent among African American, Hispanic, and Native American populations. As a Hispanic female, Ms. B is from a community with over-representation of COVID hospitalizations and mortality secondary to health disparities and care inequity.[23] The age-adjusted hospitalization rates for COVID in the United States were highest among Latino communities as compared to any other ethnic group.[24] Latino populations have notably higher rates of COVID mortality than White populations.[25–27] Of relevance to Ms. B's pancreatic cancer diagnosis, Latino patients with cancer in the United States are more likely than White patients to become infected with COVID.[28] Of important public health recognition is that Latino populations have been reported to have higher rates of vaccine hesitancy specific to the new COVID vaccine.[29,30] This is particularly worrisome in the setting of some states announcing a policy that American citizens should receive COVID immunization prior to immigrant populations.[31,32]

Mistrust in the care system represents an undercurrent to Ms. B's son's concerns as he worries that his mother is being excluded from receiving the COVID vaccine because of her ethnicity even though she is a resident of a long-term care facility. He worries the vaccine decision perpetuates life-long inequities in health care their family and community have suffered. Equity-informed responses to the impact of COVID must recognize and respond to the care needs of communities already bearing the brunt of health care disparities now disproportionately burdened by the pandemic.

The compassion and competence of hospice practitioners should translate into communication and care which garners trustworthiness with particular attention to cultural needs of communities already under-served by hospice teams.[33] Latino patients are underrepresented among palliative care and hospice patients relative to the United States population with recognized impact of geography and access.[34–36] The patient's son's reference to previous culturally incongruent interactions warrants consideration of the role for improved care and proactive communication (in the family's chosen language) partnered with cultural humility.[37] Ms. B's son has experienced care inequities in the past which warrant a trauma-informed compassionate consideration to the family's current hospice experience.[38,39]

Hospice Goals. The philosophical model of hospice is one focused on supportive care and comfort within the larger context of honoring patient preferences and goals. Preventive care is to be reasonably maintained while a patient is enrolled on hospice.[40,41] Seasonal influenza, Hepatitis B, and pneumococcal vaccinations are recognized as reimbursable covered services when furnished to Medicare beneficiaries by a hospice agency.[42] COVID vaccines as approved under Emergency Use Authorization processes in the midst of a global pandemic are not perfect correlations with other existing vaccine products. Still, the precedent for vaccine delivery for patients enrolled in hospice includes offering annual influenza vaccination for flu prevention as standard of care and considering zoster or pneumococcal vaccinations within appropriate clinical context. Unless there is medical indication otherwise, children enrolled in hospice routinely remain on a childhood vaccination schedules as standard of care with the ability for hospice providers to code for immunizations as preventive health care.

Ending the pandemic requires vaccinating populations.[43] Categorically withholding the COVID vaccine from patients enrolled in hospice care risks the opportunity to protect not only patients but also health care workers, other patients, and care setting visitors. Vaccination in a congregate setting of a nursing home with hospice services offers the hospice staff and patients the benefit of reduced transmission.

Case Conclusion

Ms. B's son contacted her oncologist who then advocated with the hospice team for Ms. B to receive the vaccine as a nursing home resident.[44] Ms. B's hospice nurse then met with Ms. B to further elicit her values and preferences. The hospice team set up a family meeting to learn from Ms. B and her son about the family's experiences with hospice care and how the current lack of access to the COVID vaccine was perceived as inequitable.[45] Her nurse met with the medical director, citing the authoritative vaccine allocation triage standard, the oncologist's perspective, the son's concerns, and the patient's personal preferences. The medical director agreed to adhere to the vaccine triage allocation guidelines and honor Ms. B's values and preferences. Ms. B's son was present when his mother received the vaccine, recognizing the event as meaningful for his mom and family.

Comment

Providing the COVID vaccine to Ms. B while she is a resident in the nursing home promotes vaccine access to all who fit within its allocation guidelines and as such is an ethically strong practice. This approach respects the expert vaccine allocation recommendations, regards patient preference, upholds the hospice philosophy, and fosters inclusion and health equity. Categorically refusing to offer COVID vaccinations to patients enrolled in hospice is ethically problematic. Unspoken biases can haunt the "bedside" micro-allocation decisions of individual practitioners. While individual providers may desire to prioritize the preferences of patients and their family members, these preferences may practically be challenged by a low vaccine supply. Individual providers will want to extend the beneficial reach of the available vaccine supply but this is ideally at a population-level view. Allocation guidelines exist to help determine who should be prioritized at a population-level.[3–6] The evidence-based, ethical frameworks for COVID vaccine allocation wisely prioritize total lives saved above life expectancy or life-years saved.[14] Prioritization of life-years saved above total lives saved jeopardizes principles of distributive justice (maximizing benefit, respect for human dignity, promoting justice) and the procedural values of a fair, consistent, transparent process of allocation.

The range of ethically justifiable options necessarily would consider both personal and public health benefit-burden assessments (Table 1). For example, if Ms. B were not a hospice patient or nursing home resident, it

Table 1
Considerations in COVID Vaccine Administration for Hospice Patients

- Patient preference (goals of care)
- Family caregiver perspectives
- Anticipated prognosis and life expectancy
- Risk of death or serious illness if patient contracted COVID
- Potential benefits or harms of the vaccine (immune status, allergy history)
- Risk or benefit to others (hospice staff, family members, co-residents in congregate settings)
- Vaccine allocation guideline prioritization (age, comorbidities, etc)

would be acceptable to wait to offer the COVID vaccine until she met allocation criteria based on her immune suppressed status, comorbidities, and age. If Ms. B's oncologist voiced that she would not mount sufficient immune response to the vaccine then it would also be ethically justified to re-discuss vaccine timing or even administration of the vaccine with Ms. B to ensure she would benefit from immunity. Similarly, if Ms. B were expected to die (based on reasonable medical certainty) prior to developing immunity from the vaccine, then the vaccine would not have a clear benefit to either the patient or staff and it would be problematic. This is particularly relevant given that currently there is not enough supply to meet the need of those who can benefit from it.

Strengths of the analytic approach applied to this case include its tangible, actionable nature and the focus on authoritative vaccine allocation guidance based on public health goals and population health values. Inclusion of diverse parties perspectives allowed for consideration of the patient and her family's lived experience, in which vaccine access served as a means to foster equity despite a history of health care disparities. Limitations of grounding the paper in authoritative guidance is that it may not adequately represent the theoretical underpinnings of the counter-arguments that would more fully engage a process of persuasive deliberation.

An essential follow-up task of ethics teams is to support ethical practice that can prevent or mitigate values conflicts could be prevented or mitigated before they develop. Often this is through proactive and transparent communication. Patients view their hospice care teams as an important source of medical information for thoughtful decision-making, particularly surrounding supportive care which extends even to vaccination practices. The way that hospice teams discuss the COVID vaccination with patients and families should reflect the widely held values and priorities of the field.

Inoculation theory in social communication explains how an attitude or belief can be protected against persuasion or influence,[46] similar to how a patient can be protected against a disease through safe and controlled pre-exposure. Caring vaccine communication with families of patients enrolled in hospice allows for a valence of scientifically guided and relationally-informed messaging which can be personalized to each individual patient. Thoughtful communication about public health-based triage processes, personalized by hospice teams as caring community members and advocates for patient-preference, parallels the medical concept of inoculation as a dose of early ethical messaging now has trust-preserving and equity-affirming potential later.

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