Ethical Decision Making in Long Term Care: A Guide

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A subcommittee of Pioneer Network's Council of Elders set out to explore two dilemmas that are currently affecting long term care communities: vaccine hesitancy among staff and indoor visitation for elders. The goal of this paper is to show how ethical principles can be used as a guide for discussion of complex dilemmas. While we acknowledge that there are no "right" answers for every community, we aim to demonstrate approaches that allow for airing diverse and potentially conflicting views on the way to arriving at ethically responsible decisions. It is our hope that this same framework will prove fruitful for approaching other dilemmas.

Ultimately, the elder's well-being is the guiding star of ethical decision-making. Ancient mariners (prior to GPS) used to begin to figure out where they were by locating the north star, the fixed point in the heavens. This was a starting point, as well as a perspective to return to when it seemed they had veered off course. Similarly, in ethical decision-making, it is often necessary to refer back to the well-being of elders when we become mired in complex and confusing considerations, or when various stakeholders seem to be moving in different directions. It is still most important to honor and highlight the voices of the people who live in these communities.

In an effort to be transparent and share the pain related to difficult decsions during the pandemic, our group has worked to collect stories that share the good and the bad with all the thorns. For each primary dilemma explored here – vaccine hesitancy among staff and indoor visitation for elders – we will first use one story and then analyze the ethical issues contained therein. Other relevant examples will be presented later in the Appendix.

Ethical Principles

The principles below are derived from those provided in *"10 Ethical Principles in Geriatrics and Long-Term Care"(see Appendix).* Our group developed a matrix to use when deliberating over tough decisions on the basis of ethical principles. These principles can be adapted for use in long term care communities. Using the elder's well-being as the guiding star provides a framework regarding how principles can be weighed.

Guiding star: Well-being of the Elder

Beneficence – do right
Non-maleficence - do no harm
Futility of Treatment – informed about consequences
Confidentiality – must be absolute
Autonomy – choice with consequences
Physician-Patient relationship – fidelity and confidentiality
Truth-telling - honest communication as fundamental
Justice
Non-abandonment

Limited resources
Utilitarianism – being absolute
Fairness or uniformity in approach
Dignity – avoiding surplus safety and excess disability

Vaccine Deliberation and Hesitancy Among Staff

After COVID 19 vaccination began in December 2020 in the nation's nursing homes, it was identified that well over 80% of elders and approximately 38% of the staff would take the vaccine. (Hernandez, K., PEWtrusts.org., April,1,2021, *Just Half of Long-Term Caretakers Are Vaccinated Against COVID,* https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2021/04/01/just-half-of-long-term-caretakers-are-vaccinated-against-covid) This staggering difference in vaccination rates caused many who operate long term care communities to ask difficult questions: *How does a provider encourage vaccination among staff members? Is it ethical to mandate vaccination as a condition of employment? Do individuals who live in nursing homes have the right to refuse to have unvaccinated staff take care of them?*

Reasons for vaccine hesitancy among staff were numerous and varied. Some had long been uncertain about vaccines and had not always vaccinated their children or themselves. Others verbalized fear of vaccination, being unable to commit to an unknown, religious concerns, childbearing considerations, worry about having to miss days at work and lose income due to a vaccine reaction and questions about the emergency status of the vaccine. Still others expressed a lack of trust in government and their organization's leaders, worry that the science had been hurried, concern about abuse by medical professionals of African Americans in the past, and anxiety about unanswered questions such as long-term side effects.

Many approaches to reducing hesitancy surfaced across the country: education, peer pressure, listening to staff and answering their questions, relationships in the collective community, monetary bonuses, special status for the vaccinated, and using staff converts or trusted elders as key influencers. The following story was chosen for the multi-layered responses offered by a seasoned leader.

A report in the *New York Times* (*Goodnough, Randy., March 21, 2021* https://www.nytimes.com/2021/03/28/health/nursing-home-covid-19-vaccine.html), described how a nursing home administrator, Tina Sandri of Forest Hills Nursing Home of DC, faced a daunting dilemma when only half of her staff members agreed to receive the vaccine and the other half declined. The majority of her staff were African American. Ms. Sandri eschewed the authoritarian temptation of making vaccination mandatory (or face termination), and equally resisted the enticing bribery tactic of offering cash bonuses and other benefits as patronizing and not respectful of deep rooted fears and beliefs.

Ms. Sandri decided to meet with staff one to one, intending to meet them where they were at, without judgement but with empathy. For example, to the analytically inclined she showed the science, the empirical data. For those concerned with past medical abuses that afflicted Black communities in the past, she played testimonials of prominent Black leaders and brought in members of the Black Coalition Against COVID-19. Relationship-oriented staff were sensitively

reminded of the vision of a return to family reunions for them personally as well as for their residents starving for human contact. Over a several week period the vaccine percentage for staff rose to 79%, exceeding the American Health Care Association's goal of 75%.

An ethical tenet that is salient in this example is autonomy, i.e., that individuals have a right to self-determination; to make decisions about their lives without interference from others. An authoritarian style would have repressed individual choice. While some would have gotten the vaccine in response to the threat of losing their job, there would likely have been turnover as others resigned, exacerbating the workforce shortage.

Coerciveness such as bonuses might have had some effect but with the consequence of not honoring personal realities of vaccine resistance, engendering underlying contempt and disrespect for the leader. Ms. Sandri's leadership acknowledged autonomy, yet gently, through acceptance along with lucid depiction of the consequences of their choices. Gradually, she garnered their trust by providing information that spoke to their individual concerns. A successful outcome was realized, person-by-person – a true win/win.

Indoor Visitation

During the initial surge of the novel coronavirus in March and April of 2020, long term care communities across the country closed for visitation. Compassionate visits, when an elder was at end of life, were allowed, but not without hesitancy. We all assumed this plan would be short lived, but nursing homes and assisted living communities generally remained closed for over a year. Families, consumer groups and the elders who lived in nursing homes were outraged, however, local and state health departments insisted nursing homes remain closed to visitors as outbreaks of the virus continued.

In the summer and fall of 2020, outdoor visitation was allowed according to guidance provided by state health departments. Window visits with families and friends became the norm. In most states, elders who left their community were required to quarantine for 14 days upon their return, creating more loneliness, depression and despair. Masks and social distancing set the stage for daily living. Once an outbreak occurred, visits to the dining room and communal activities were halted. Eventually, as the virus exploded in November and December, most people living in nursing homes across the country found that they were confined to their room *for their own protection*.

At this juncture, safety measures clearly took precedence over considerations of well-being. Elders in nursing homes were heartbroken. The National Conumer Voice for Quality Long Term Care quotes Stephanie, a nursing home resident: *The boredom … never seeing a family member. When you're at this age and this stage of your life those things can actually have a bigger impact on your health than worrying about catching the coronavirus. And if you're depressed and so on, this is going to really affect you.*

In the winter of 2020-2021, advocacy groups, ombudsmen and family members increased the pressure on state agencies and the Centers for Medicare & Medicaid Services (CMS) to open nursing homes for visitation. Again, there was a difference of opinion between providers and

those advocating for indoor visitation. Some states adopted essential caregiver programs for families to be trained in the use of personal protective equipment (PPE) to provide psychosocial and other support for their loved ones. In March 2021, CMS issued guidance on indoor visitation which met with questions on behalf of state agencies and providers. Providers waited for additional guidance from state agencies and by late March and into early April nursing homes and assisted living communities developed plans to provide for visitors by appointment in elders' rooms, if private, or in designated common areas.

Ethical dilemmas surrounding visitations are especially wrenching for nurses, having just lived through the trauma of COVID stealing the lives and health of residents and staff alike. Knowing the "buck stops here," they will be held responsible should there be a break in the rather complex (and untested) protocols related to increasing visitation. They fear that if COVID enters again, there will be a return to the overwhelming stress of staffing problems, quarantining, arranging testing, PPE protocols and the like. Yet nurses who have witnessed the isolation, heartbreak, loneliness, and devastation both physically and emotionally on those living in nursing homes are aware of how vital it is to open up and let visitors in for the sake of elders' well-being.

The guiding star certainly points us in an approximate direction, but it is still difficult to find our way in the details of this ethical quandary. How do we weigh the benefits and burdens of opening up against the risks to elders? How do we help nursing home leaders deal with their fears so that their fear does not become the major deciding factor? What ethical principles and what process can guide us in achieving reasonable and responsible decisions related to opening up visitation? High vaccination rates for elders provide some assurance that outbreaks of COVID-19 can be minimized and the internal community can open and operate in a way that elders have meaningful engagement, but how much control should be exercised over visitors?

The following narration depicts the on-the-ground struggle of a leader who has her eye on the guiding star:

During the worst of the pandemic, we experienced a 98% outbreak. Eighty-six elders had the virus within one week and seventeen died. Now I feel stress and anxiety with strangers coming in my doors for visits. We can't ask them if they had a vaccine or have been tested. Will they bring in the virus? We are only opening visitation Monday through Friday, only one visitor at a time. Then there is another visitor an hour later. Visits take place in our dining room or small conference room. Family and elders are as happy as they can be and so are joyful. We are super conservative about visitation because of our experience. It's hard to open wide and then have new guidance. I'm going to stay the course of being conservative. I may get a tag or lose my job, but I am not budging. People need to see my level of concern. We are protecting the elders and taking it seriously. The elders are amazing. It was so hard when they couldn't come out of their rooms. This is not how it's supposed to be. Now no one wants to come to the dining room, they are used to trays, used to room trays. Now we have schedules when elders can come to the dining room. Our current vaccination rate is 95% for elders and 50% for staff. Telling the stories are important, it's cathartic. Everything is a no because we are so scared that we'll return to the same, case after case and huge outbreaks.

Clearly, this administrator wants to avoid further harm identified in the principle of non-maleficence. The ethical mandate to preserve the elders' autonomy is not paramount because of her past experience of an uncontrolled outbreak. She is able to be transparent about how her fear conflicts with her desire to enhance elders' joy in being reunited with family visitors as often as possible. Her honesty (truth-telling) is an ethical strength which enables her to join the enthusiasm of her staff toward finding creative strategies for opening up, such as having one visitor at a time and restricting where the visits take place.

A Call to Action

Our call to action is for nursing home and assisted living providers, partners and stakeholders to appreciate the meaning and outcomes when ethical principles are used in decision making. This reduces friction while providing for respectful disagreement and thoughtful deliberation. Using ethics as a foundation produces powerful outcomes for elders, staff and providers.

The voice of the elder matters, as does input from those who provide direct care along with those who manage the provision of care. With juxtaposed points of view, no matter how polarized, ethical principles help us find our bearings. Ethics committees in nursing homes have been shown to be productive and safe places to air differences and work through dilemmas in fresh ways. Nursing homes have many complex issues that can benefit from ethics committees, beyond the pandemic. Here are some necessary actions we have identified for facing complex dilemmas as they arise:

1. Use the well-being of the elder as the guiding star in decision making.
2. Be the guardians of the care.
3. Create access to an ethics committee in every nursing home.
4. Deliberate thoughtfully and include the voices of elders.
5. Be person-directed in approaches without reverting back to instutionalzation and surplus safety during difficult times.
6. Identify the benefit versus burden.
7. Leadership needs to be focused on ethical principles through all dimensions of governance.

As we close this dialogue, we understand that the specific dilemmas explored here will continue to evolve. We are confident, however, that the ethical principles will endure across shifting circumstances and continue to provide meaningful guidance.

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We wish to convey special thanks to the Colorado Longterm Care Community Ethics Committee for generously sharing resources and inviting our group members to partake of their lively, informative, and inspiring monthly discussions. They set an example of dignity and thoughtfulness for every ethics committee. We are indebted to them for sharing their wisdom and welcoming our participation.

Appendix

*Additional stories

*Example of an ethical decision-making matrix

*10 Ethical Principles in Geriatrics and Long-Term Care

*Pioneer Network https://www.pioneernetwork.net/about-us/mission- vision-values/

*Planetree https://planetree.org/wp-content/uploads/2021/05/Family-Presence-Policy-Decision-Making-Toolkit.pdf

*Institute for Patient and Family Centered Care https://www.ipfcc.org/bestpractices/covid-19/IPFCC_Family_Presence.pdf

*Altarum survey https://altarum.org/sites/default/files/uploaded-publication-files/Nursing-Home-Resident-Survey_Altarum-Special-Report_FINAL.pdf

Story #1 *Safety and Joy*

Opening for indoor visitation for one Director of Nursing created a sense of fear for her. She wanted to protect the elders and staff from serious illness. So far, they had not had an outbreak of coronavirus, and she was committed to preventing one. Then in December and January vaccinations began and over 90% of the elders took the vaccine, leaving just 3 elders without vaccination. It was an impressive rate, and she knew it was a positive sign for their long term care community. New guidance arrived from CMS and the state health department asked them to open their doors and not restrict visits for elders. It was a total flip flop from previous guidance, sending her into a tailspin. She just couldn't imagine eliminating quarantine. Masks were required but families could visit in elders' rooms. She still was fearful. Many other leadership team members, staff, physicians and consultants all talked about visitation. Still, reluctance was her message. For a couple of weeks many others talked with her, engaging in a real and honest conversation. Then one day she came through, saying, "For the elders I know visitation is the right thing and eliminating quarantine is too". No more 14-day quarantine for new elders moving in who had been vaccinated or those leaving to visit family who agreed to social distance and wear masks for visits. "I know it's the right thing to do and I'm ready now." She had to have time to process through her decision making.

Story #2 *Using Learning Circles and Relationships on Neighborhoods*

One experienced Director of Nursing shared her concern with vaccine hesitancy among direct caregivers. This was a huge worry for her. She knew there had to be a way to get the COVID-19 vaccine rates close to 90%. This Eden Alternative registered home had been reorganized into six neighborhoods where learning circles were held with staff and elders who worked and lived in

these neighborhoods. Prior to the pandemic, these neighborhood learning circles had been where communication flowed and decisions happened. Resuming this practice – to give voice to everyone – seemed like the best approach to explore how vaccination was being perceived. They talked about vaccines and all the fears and the successes. Staff trusted the information they gleaned from the elders, as relationships had developed in many cases over the years. Hearing the elders' positive experiences with vaccination gave them reassurance that taking the vaccine would be okay. The staff started slowly taking the vaccine over the next month, and the overall staff vaccination rate improved exponentially with an additional 30% getting vaccinated. Returning to person directed practices with wise leadership resulted in significant improvement in vaccination rates.

In support of an ethical model for decision making, autonomy is paramount in discussing vaccination with staff. Preserving choice while holding to the ethical standard of non-abandonment allowed the leadership team to show how committed the organization was to staff. In the learning circles, the elders were able to share their own experiences and reactions to taking the vaccine. They were able to express how important it was to them that staff would be able to protect their own health and safety by accepting vaccination. It was also clear that the elders were relying on the staff's beneficence to avoid the potential harm of receiving direct care from someone not vaccinated, and also to avoid illness that could come from working alongside others who were not vaccinated.

Story #3 *New models of living can prevent outbreaks*

For a small house model nursing home community in Colorado, practicing consistent staffing allowed them to essentially create a bubble, resulting in no outbreak of the coronavirus over the first year of the pandemic. On this campus, there are four houses where 12 elders live, with caregivers dedicated to each of these houses, supported by a nurse and a few others who share duties with another house. Elders each reside in a private room with a private bath, with communal space for dining, a living room, den and a kitchen. Elders see the same nurses and caregivers each day. Early steps taken by the Director of Nursing and others on the team, using quarantine, testing, and monitoring to prevent the virus from spreading, proved fruitful. Some staff reported symptoms but stayed home and quarantined for the required 14 days. Visitors did not visit and by Fall 2020, the county had the highest rate of COVID-19 in Colorado. During all this time, new elders moved in and the health department surveyed for infection prevention. This community was diligent and reported no virus.

This outcome is extraordinary and remarkable but predictable. Because of the small size of each house and minimizing how staff were shared between the houses, they were able to get through without the heartbreak and the losses. The leadership team showed the same commitment and fear seen in other LTC staff. They were under a great deal of stress, each day thinking will this be the day that a report returns positive? Never giving up and being willing to discuss what the next steps were, day after day, got them through.They adhered to the ethical principles of autonomy and beneficence, similar to the other stories, and their vaccination rates among staff reached 60% after three vaccine clinics. The medical director continues to act as an educator, helping staff to appreciate the benefits of vaccination.