A Review of the Medical Ethics Surrounding COVID-19 Lockdowns in Personal Care Homes and the Impacts on Those Living with Dementia

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Perspective

The impacts of the COVID-19 pandemic on personal care homes has played out daily in the media headlines across the country. Although Manitoba seemed to avoid the worst of this early on in the pandemic, recently the province has seen a disturbing surge in overall case levels (Government of Manitoba, 2020). This rise in COVID-19 cases in Manitoba has forced personal care homes to once again lockdown and restrict not only all visitor access but also limit social interaction among the residents themselves. When looking at this situation broadly, locking down all personal care homes seems to be like the obvious decision to make. Residents in personal care homes represent one of our most vulnerable populations and the virus has been shown to spread quickly with serious medical impacts to this group. Significant virus spread in these personal care homes could easily overwhelm our healthcare system and lead to unnecessary deaths. Clearly the decision to lockdown the personal care homes can be readily justified as a means of protecting not only this vulnerable group but also supporting the larger community who either provide healthcare or are requiring healthcare for other non-COVID-19 related reasons. While the above is true, the decision to do this is far from being straight forward. The impacts of these lockdowns are far reaching and go way beyond just the containment of the virus. There is a fine balance between maintaining the emotional and mental well-being of an individual living with dementia and managing the physical health of the greater population.

To better understand the complexity of this decision, it is important to have an understanding of what living with dementia means. Dementia is a neurocognitive disorder in which an individual experiences a decline from a prior cognitive level (Shwartz, 2018). In Canada, there are over 500,000 people currently living with dementia and approximately 25,000 people are diagnosed with dementia every year (Alzheimer Society of Canada, 2020). Considering that approximately 37 million people live in Canada, the number of people living with dementia represents a significant proportion of the population (Statistics Canada, 2020). Those with dementia tend to have a progressive decline in their ability to carry out the activities of daily living, engage in social functioning, or elicit adequate decision making (Shwartz, 2018). While individuals with dementia may have difficulty carrying out these everyday tasks, it is important to acknowledge that many of them still have values, preferences and beliefs that should be

honored. In personal care homes, many residents experience dementia ranging on a spectrum from mild to severe cognitive impairments. Many of these residents rely on social interaction, as social enrichment can be a key rehabilitative measure in slowing down both physical and mental decline in individuals with dementia (Muntsant-Soria et al., 2020). As well, in order to uphold self-esteem, it is important for those with dementia to maintain existing social relationships and continue to engage in things that are important to them (Alzheimer Society of Canada, 2020). Isolation and loneliness can contribute to anxiety and depression in individuals with dementia, as well as can contribute to further cognitive decline in older adults (Cagnin et al., 2020). Maintaining normalcy and continuity of care is also crucial in this population group as abrupt changes in lifestyle and day to day routines can significantly contribute to fear and anxiety (Cagnin et al., 2020). With that being said, health care providers have "an ethical priority in the care of people living with dementia to maximize the likelihood that they will have opportunities to live lives reflective of their values and maintain active, central roles in decision making" (Wilkins, 2017, p. 637).

Locking down personal care homes ultimately supports the need to contain the virus for the betterment of our entire community but in doing so it sacrifices many of the supports that individuals with dementia need. The lack of visitors and social interaction among residents can lead to loneliness and self-isolation. This self-isolation may also increase the risk of developing dementia (Xiang et al, 2020). In fact, feeling lonely, as opposed to actually being alone, has been shown to increase risks of cognitive decline (Holwerda et al, 2014). Infection control practices can conflict with quality of life and the rights of residents (Iaboni et al, 2020). As well, in many personal care homes family members act as additional support, assisting with tasks such as feeding, personal care and monitoring. With the lockdown, these supports are lost and with increasing workloads and staffing shortages due to COVID-19, this can cause some residents to experience a decrease in quality care. In the event of serious illness, these residents will miss not having family members close at hand and may even be forced to die alone. The effects of a lockdown are particularly difficult for those living with dementia, who may not comprehend the extent as to what is going on (Iaboni et al, 2020). It is unreasonable to not consider the long lasting effects that locking down personal care homes can have on the residents who live in them.

So what should be done? Is it right to lockdown personal care homes amidst a global pandemic or do the longer term impacts to those living with dementia outweigh the common good of society? While the answer to this may not be clear, this paper will present an in-depth analysis of the ethical dilemmas associated with locking down versus not locking down personal care homes in a global pandemic in relation to the four pillars of ethics: autonomy, beneficence, non-maleficence and justice. The exploration of the

role of health care providers, specifically physician assistants (PAs), in this situation will also be discussed.

Pillars of Ethics

The topic of ethics can have multiple meanings. In a broad sense, ethics can be defined as "the study or examination of morality through a variety of different approaches" (Bennett-Woods, 2017, p. 405). Ethics can further be defined through the lens of "medical" or "clinical" ethics, which refers to "the field of study and applied practice toward ethical issues that arise in the practice of medicine" (Ballweg et al., 2018, p. 426). The four-principle approach to medical ethics, outlined by Beauchamp and Childress (2013), serves as a framework for evaluating moral behaviour in medicine and includes the following principles: autonomy, beneficence, non-maleficence and justice. These four pillars of ethics can be analyzed in the context of personal care home lockdowns during a global pandemic.

Autonomy

Autonomy is regarded as respecting people's right to make choices that are meaningful (Oberle & Bouchal, 2009). It is showing respect for individuals and valuing their wishes (Bennett-Woods, 2017). When considering the four biomedical ethical principles, autonomy is key and should be given primary emphasis whenever health care decisions, or decisions in general, are being made. In older adults with dementia, maintaining autonomy may be difficult depending on their competency and capacity to make decisions. At times, a substitute decision maker or a medical proxy may be needed in order to ensure that adequate care is provided to the patient. None the less, there needs to be a concerted effort to preserve autonomy whenever possible and if autonomy has to be compromised in certain situations, involving the individuals in the decision making process and allowing them to have some choice should be encouraged.

When it comes to personal care homes, choosing to lock them down during a pandemic has the potential to significantly impact the autonomy of those older adults living with dementia. In a lockdown situation, residents of personal care homes are not able to see their loved ones for very long periods of time nor are they generally allowed much social interaction with their fellow residents. While this is likely something that they do not want, they do not have a say in this decision. It is something that is basically imposed on them and thus their autonomy is compromised. This is especially significant to those living with dementia, as they may not be able to comprehend why they cannot see their family and may more acutely feel this loss of control over their own freedom to choose.

If personal care homes were not locked down, this would allow for the residents ability to make their own decisions on whether or not they wanted to see loved ones rather than unilaterally locking down the facility. This would give them a greater sense of control over their environment and would certainly be in alignment with supporting and encouraging autonomy to the greatest extent possible. Often times personal care homes try to allow residents to make many personal choices whether it be what to wear, what activities they want to take part in, or what television show to watch. These decisions, while impactful to the resident's day to day life and help preserve autonomy, are generally self-limiting and do not have the ability to do long-term harm. Unfortunately the decision to see loved ones during a pandemic is not an easy one and does require a level of cognitive skills to properly assess the risks associated with the end decision. Older adults living with dementia may have difficulty understanding and weighing the risks associated with the virus and contact with other individuals (Iaboni et al, 2020). This diminished ability to make an informed decision weighs heavily on whether they should be given the autonomy in regards to allowing visitors or not. As such, their autonomy may have to be compromised in order to do what is best for them. This is similar to someone who is in the early stages of dementia who has their drivers license taken away from them. They themselves may feel like they are a good driver, but their lack of cognitive ability to assess the situation and the risks properly, compromises their ability to make the right decision for both their own personal safety and the safety of others. If autonomy of an older adult has to be compromised, it is still important however to include them in conversations as to what is going on, regardless of if they understand it or not. Just because we may not be able to maintain autonomy does not mean dignity and respect are neglected.

Beneficence

Beneficence is acting with the best interest of the other in mind or doing what is best for the patient (Ballweg et al., 2018). According to Beauchamp and Childress (2013), this concept means that "one ought to prevent evil or harm; one ought to remove evil; and one ought to do or promote good" (p. 151). While health care providers have an obligation to make medical decisions based on what they believe is best for the patient, determining what is "best" for a patient can often present as a bit of a grey area. Some health care professionals may think that they are doing what is best for a patient, simply by doing whatever they can to help keep the patient alive. Although their intentions may be good, this is not necessarily aiding in the principle of beneficence. In fact, health care providers may be engaging in the act of paternalism if they start "making decisions for patients in their patients' best interests…without their consent" (Oberle & Bouchal, 2009, p. 14). Pellegrino and Thomasma (1998) have suggested that the biomedical good (what

the physician or team recommends) is a subsidiary good to the patient's perception of the good. As such, while it is important for the health care team to analyze what they believe may be best for the patient, it is more important for them to get an understanding as to what the patient's own perception of good is, as this will aid in providing individualized care that is best for the patient's specific needs.

When it comes to personal care homes, choosing to lock them down during a pandemic does have the potential to aid in beneficence. This is because locking down personal care homes would reduce the number of people entering them and thus should help to decrease the chances of the virus spreading amongst the residents. Many residents living in personal care homes have a collection of co-morbidities that make them more susceptible to experiencing adverse health outcomes if they contract the virus. It is also possible that many family members of residents are worried about their loved ones in personal care homes and thus they believe that aiding in beneficence consists of the province doing everything in their power to ensure that residents do not contract the virus, even if that means locking down all personal care homes. In many instances, ensuring that residents stay healthy and free from disease would be aiding in beneficence. However, locking down personal care homes does have the potential to neglect beneficence depending on the specific wishes of the residents. For example, for some residents, it may be more important to be able to spend time with their loved ones in their finite period of life left than to spend time in lockdown to ensure they do not get the virus. The personal care homes can at times be a very lonely place for residents and thus some of them may rely heavily on their family members to provide them a sense of normalcy in their life. Avoiding contracting the virus might be meaningless to a resident if their emotional and mental well-being is compromised in the process.

If personal care homes were not locked down, then this may also have the potential to aid in beneficence. If all a resident truly cares about is being able to see their family or engaging in social interaction with other residents in the facility, then not locking down personal care homes may actually be what is best for the resident. It would promote quality of life, rather than focusing on remaining free from disease. As well, engaging in social interaction may act as a rehabilitative mechanism that would help slow their physical and mental-decline, and thus contribute to beneficence (Muntsant-Soria et al, 2020). If a resident is nearing end of life, it might also be more important for them to spend the last few days with their loved ones rather than isolate from the virus. However, all residents may not have the same opinion regarding locking down personal care homes. Some residents and their family members may be worried about potential exposure to the virus and would prefer having a period of isolation over spending time with loved ones. As such, beneficence may not be fulfilled in those who wish to be protected from the virus at all costs.

Non-maleficence

Non-maleficence refers to the obligation to do no harm (Beauchamp & Childress, 2013, p. 151). In general harm can be related to pain, disability or death (Bennett-Woods, 2017). However, harm can be sometimes difficult to define and at times certain harms can be unavoidable in order to adequately treat a patient (Bennett-Woods, 2017). Regardless, health care providers must do their best to ensure that undue harm is not elicited.

When it comes to personal care homes, choosing to lock down them down during a pandemic does have the potential to aid in non-maleficence. This is because locking down prevents excess visitors from entering personal care homes, which will thus help to reduce to the risk of viral transmission to vulnerable residents. Since doing no harm involves not inflicting pain, disability or death onto someone, ensuring that residents do not get COVID-19 would in part be aiding in non-maleficence. However, locking down personal care homes also has the potential to go against non-maleficence as there is a high potential for unintended harm (Iaboni et al., 2020). According to Manca et al (2020), the COVID-19 pandemic and the associated social isolation that comes along with it, has a wide negative impact on the mental well-being of older adults with and without dementia. In addition, "worsening or emergence of new neuropsychiatric symptoms was found in a substantial proportion of patients with a cognitive decline as a result of social isolation" (Manca et al., 2020). What is important to note here is that harm does not only encompass physical health; it includes all forms of health such as emotional, mental, spiritual, and social health. As such, while the residents may not be harmed physically from COVID-19, they may experience psychological harm related to self-isolation measures. To add to this, some personal care homes are experiencing staffing shortages and are not able to adequately meet the needs of the residents (Davidson & Szanton, 2020). If families are not able to enter personal care homes and help assist with the care, then adverse outcomes may happen due to lack of support and resources. This includes residents not being adequately fed, changed, or medically assessed. Residents living in personal care home who are nearing the end of their life might also not be able to have any family members at their bedside during their passing. This can make for a very lonely and scary experience for the residents, as well as has the potential to have an impact on family members who are not able to say goodbye to their loved ones.

If the personal care homes were not locked down, then this may also have the potential to aid in non-maleficence. If visitors are able to enter personal care homes, then they would be able to assist the health care staff in providing care for their loved ones. For example, they could spend time feeding them, they could help change their brief, or they could help administer their medications. This could help to reduce the chances of adverse outcomes occurring due to staffing constraints and increased workloads.

However, this also has the potential to go against non-maleficence as increasing the number of visitors in the building increases the transmission of the virus, especially if visitors were to enter the building when they were symptomatic. Quarantines and lockdowns have been proven to play a crucial role in controlling the spread of disease during pandemics (Malheiro et al, 2020). Since each individual has a right to good health, allowing visitors to enter personal care homes during a pandemic, and thus potentially causing harm to these residents by spreading the virus, may be breaching non-maleficence.

Justice

Justice emphasizes fairness and equality among individuals (Ballweg et al., 2018). This means that patients have a right to receive care that does not discriminate against them as an individual or as a member of a group of individuals (Bennett-Woods, 2017). Everyone should have the ability to access the same level of care, regardless of who they are (Bennett-Woods, 2017).

When it comes to personal care homes, choosing to lock down them down during a pandemic may be considered unjust for the residents living in these homes if other population groups are not having to endure these same restrictions. If other members of society are free to visit with their loved ones as they please, then this might not be fair to those living in personal care homes who do not have a choice as to whether they can see their loved ones or not. It could be argued, however, that since the lockdown impacts all residents in the home equally that some justice has been preserved. In a lockdown, you do not have a situation where some residents get to see family where others do not. As such, all residents are experiencing similar realities. Locking down personal care homes may also aid in justice as everyone has the right to equitable access to disease prevention. Treating older adults as equal members of society and protecting them from the virus regardless of their age or comorbidities, would be acting with justice in mind.

If the personal care homes were not locked down, this could also potentially be unjust to those residents living in these care homes. It is unfair to not protect a portion of society simply because they are of advanced age. Each individual life matters and therefore not locking down personal care homes for the convenience of others can be deemed unjust. Not locking down personal care homes may also create conflict as some family members might not want any visitors entering the building in order to protect their loved ones, while other family members of have a dying loved one might want to be by their side during their passing. As a result, it may not be fair to allow visitors in personal care homes as this would spread the virus to vulnerable residents, but it might also be unfair to not let family members see their dying loved one for the last time.

Considerations for PAs

Pandemics are unprecedented times in which the lives of many are at stake. In particular, pandemics can present a series of ethical dilemmas that have to be handled very critically and thoughtfully. As health care providers, PAs play an active role in making ethical decisions across the span of their career. In fact, PAs have a legal and regulatory requirement to practice in alignment with the Canadian Association of Physician Assistants (CAPA) Code of Ethics. While the decision whether or not to lockdown personal care homes goes far beyond an ethical decision that a PA would have to make in practice, this does not mean that PAs cannot contribute to ethical decisions involving older adults with dementia on a smaller level. If anything, this pandemic has played a very important reminder to always consider all the ethical principles involved in a given situation. While it may be important to lockdown personal care homes, PAs can work towards maintaining the pillars of ethics in older adults with dementia as much as possible. Whether it be implementing resources to help with social isolation, such as through video-conferencing platforms, or simply being an open ear for someone to talk to when they are feeling lonely. It is the small yet meaningful things that can still be done in order to lessen the burden of the pandemic on these vulnerable groups of individuals and society as a whole.

Conclusion

In conclusion, the decision as to whether to lockdown personal care homes during a pandemic creates an ethical dilemma with respect to older adults living with dementia. While there are many factors that need to be considered upon making this decision, it is important to lockdown personal care homes during a pandemic in order to achieve the greatest good for the least amount of harm. To be able to do this, however, additional supports and resources need to be implemented in order to reduce the negative effects related to social isolation in lockdown. In particular, special attention needs to be paid to vulnerable population groups, specifically those older adults living with dementia, as they may experience exceptional challenges related to this intervention.

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