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COVID-19 and Nursing Home Residents' Rights

Nancy Kusmaul, PhD

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COVID-19 and Nursing Home Residents' Rights

Nancy Kusmaul, PhD

University of Maryland Baltimore County

Correspondence should be addressed to:

Nancy Kusmaul, Associate Professor

School of Social Work, Sherman Hall 322

University of Maryland Baltimore County

1000 Hilltop Circle

Baltimore, MD 21250

nkusmaul@umbc.edu

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COVID-19 and Nursing Home Residents' Rights

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Prior to 1987 nursing home residents had no explicit rights. The Nursing Home Reform Act included a bill of rights for residents out of recognition of the steep power imbalance between residents and staff¹, and the development of learned helplessness by those who live in such settings². Born from a time when nursing homes residents were subject to physical restraints and sedation, these rights sought to give residents greater control over daily routines and social interactions². Could Covid-19 be sending residents rights back to this time?

As soon as the story about the Kirkland, Washington nursing home and Covid-19 became national news the Centers for Medicare and Medicaid Services (CMS) took swift action to protect nursing home residents³. Their press release on March 13, 2020 characterized their directives as the most aggressive and decisive, and they certainly were. They immediately restricted all visitors, volunteers, and nonessential personnel from entering nursing homes and cancelled group activities and communal dining.

While the Covid-19 pandemic seemed urgent and the risks to nursing home residents were real, these directives superseded and countered residents' rights. One of the core resident's rights is the right to spend time with visitors of your choosing. "You have the... right: To spend private time with visitors. To have visitors at any time, as long as you wish to see them, as long as the visit does not interfere with the provision of care and privacy rights of other residents."⁴

The restriction of rights is concerning, even in the face of a global pandemic. Nursing homes are required by federal regulations to provide maximal quality of life. As defined in the federal register, §483.24 "Quality of life is a fundamental principle that applies to all care and services provided to facility residents. Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and

psychosocial well-being, consistent with the resident's comprehensive assessment and plan of care.”⁵

How can residents maintain the highest practicable mental and psychosocial well-being when they are not able to connect with other human beings, including loved ones? CMS made exceptions for “compassionate cases” which were left to the nursing homes’ discretion.³ The example they gave was for end-of-life situations.³ But what about the mental health effects of being cut off from spouses and children? Were residents more likely to become ill and die if they didn’t feel like they had something to live for? As many of us have learned through this COVID-19 pandemic and the subsequent isolation at home, the absence of normal markers of daily life including connection with others can leave people feeling disoriented and disconnected. It is too soon to know the long term impacts of this isolation on the mental and cognitive health of residents but there is no doubt that physical and mental health are intertwined. Resident’s rights are essential for quality of life, autonomy, and health for nursing home residents. Dr. Penny Shaw, a nursing home resident in Massachusetts, has written extensively about how exercising about her rights has improved her life, and her health outcomes.⁶

So where is the line? How can we keep residents safe while protecting their right to self-determination and choice? It is a difficult balance. As the country tentatively reopens community dwelling citizens are making their own calls on some of these things such as where is it safe to venture, with whom, and whether or not to wear a mask. So what is different about congregate care settings, especially nursing homes? The challenge lies in the ever present balance between individual rights and the common good and the desire to protect those in care.

Nursing homes and policy makers need to consider ways to allow nursing home residents control over their visitation preferences without increasing risks to all of the residents in the

nursing home. Guidelines are beginning to be developed to allow nursing homes to re-open to visitors and we can look to these guidelines for recommendations to increase safety and improve choice. Recommendations for safer reopening are outlined in table 1. [Insert table 1 here] I will also add that if the facility as a whole has not reopened to visitors, consider cohorting residents who are interacting with the outside world from residents who are remaining isolated.

Many nursing home residents who are aware of the COVID 19 crisis are feeling frightened and vulnerable.⁹ A nursing home social worker reported that staff are also feeling frightened of the idea of additional people and chances for infection coming into facilities. Nursing homes themselves fear liability and citation. These fears should be addressed through the practice of prudent precautions. Fear should not keep residents from exercising their rights.

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112 Table 1: Visitation recommendations

Visit Practices	<ul style="list-style-type: none"> • Screen all visitors for symptoms of COVID-19, such as taking temperatures.^{7,8} • Mandatory hand hygiene upon entering the facility.^{7,8} • Social distancing during the visit.^{7,8} • Require face coverings for residents and visitors during the visit.⁷
Facility Practices:	<ul style="list-style-type: none"> • Require appointments to control the number of visitors in the facility.^{7,8} • Consider time limits to control number of visitors.⁸ • Create designated visiting areas.⁸ • Consider outside visiting if feasible.⁷ • Consider physical barriers.⁷

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