

No Hugs Allowed: Isolation and Inequity in North Carolina Long-term Services and Supports During COVID-19

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Four in 10 COVID-19 cases and deaths in North Carolina have occurred in long-term care facilities. The virus has contributed to increased health complications and financial stressors for recipients of long-term care services and supports and their caregivers, negatively affecting the quality of care received and contributing to already existing social isolation.

Patient Isolation Worsened by COVID-19

In North Carolina and across the country, COVID-19 compounded already existing isolation from family and friends for older adults and those with disabilities cared for across the long-term care services and supports (LTSS) spectrum (i.e., nursing homes, skilled nursing facilities, and home and community-based services) [1, 2]. The risk of infection worsened this isolation as facilities minimized personal contact to reduce exposure to COVID-19. In order to limit the spread of COVID-19, North Carolina's Department of Health and Human Services (NCDHHS) mandated cancellation of communal activities, group meals, and in-person visitation [3]. Although necessary to preserve the physical health of patients, these policies do not prevent negative mental health effects among LTSS recipients. A more comprehensive approach would include mental health and social-support-focused policies alongside standard disease detection and prevention.

Isolation, already a serious health risk for older adults, has been linked with higher rates of clinical depression, anxiety, and even heart failure [4]. With more than 70,000 long-term care residents and staff dead from COVID-19 nationwide—accounting for 4 in 10 deaths—as of September, lockdowns and isolation have become essential to limiting the spread in these facilities [5]. Walks outside and other physical exercises are restricted for LTSS residents, causing physical deterioration of patients. With many residents unhappy with their lives in lockdown, families grapple with bringing their loved ones back home, potentially placing the burden of care on the families themselves.

Race and Long-term Care in North Carolina

COVID-19 disproportionately affects Black, Indigenous, and people of color (BIPOC) by exacerbating preexisting

inequities in income, housing, education, and other social determinants of health [6]. It is imperative to look at how these inequities affect long-term care recipients in the state, where Black individuals, in particular, account for a large percentage of residents in long-term care.

Nursing homes account for over 40% of all COVID-19-related deaths in America; Black individuals in nursing homes and other LTSS facilities may experience a larger incidence of cases and death in North Carolina [7]. As of October 11, North Carolina had 7,358 cases and 1,492 deaths linked to nursing homes [8]. Although accurate demographic data on these cases are not available, it is relatively safe to assume the cases disproportionately include Black individuals. A recent *New York Times* article supports the assumption—its inquiry into 22 states, not including North Carolina, found that nursing homes with large African American and Latinx populations were twice as likely to be hit with coronavirus as majority-white nursing homes [9]. The former—like other institutions in America—tend to be lower-rated institutions in more urban settings with larger resident populations [9].

These factors all contribute to increased risk of exposure to COVID-19 in LTSS. BIPOC-majority facilities are often lower-rated on the federal star rating system and are experiencing higher rates of infection compared with higher-rated facilities [10]. This combination of lower quality of care with heightened risks for minority populations in the face of COVID-19 confers particular disadvantages for these populations. This disparity, built in part by decades of systemic racism, depicts another way Black and other minority Americans are dying from COVID-19 at higher rates compared to white Americans.

All Nursing Facilities are not Created Equal

Whether a facility receives Medicare or Medicaid dollars has implications for facility quality, staff-patient ratios, staff compensation, and other attributes. Nationally, approximately 60% of all nursing home care expenditures are

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paid by Medicaid (43%) and Medicare (16%) [11]. Because about half of community-dwelling Americans needing LTSS are younger than 65, increased Medicaid spending makes fiscal sense as Medicare is only widely available to individuals aged 65 and older and does not cover LTSS except in limited instances [12].

North Carolinians under age 65 with physical disabilities receive around 39% of North Carolina's Medicaid dollars while the other 61% goes toward nursing home care—covering individuals accounting for four-fifths of all national LTSS spending while representing a small minority of the population [12, 13]. Variability in LTSS funding and quality has left facilities exposed to the pandemic and impacts their ability

to respond uniformly and adequately regarding testing, contact tracing, and supplies (i.e., personal protective equipment [PPE]) [14].

What About the Caregivers?

In a typical year, *formal* LTSS caregivers—individuals employed to provide care—often lack adequate wages, work multiple jobs, and care for family members [15]. The current pandemic exacerbates these issues while adding more risk of infection, loss of wages and employment, and increased stress. Again, the burden is disproportionately felt by BIPOC who are often employed in these direct care worker positions [16].

COVID-19 has negatively affected *informal* caregivers as well. Informal caregivers may be caring for older or sick family members while balancing children and a job. The typical caregiver in the United States is a 49-year-old woman caring for a woman aged about 69 years [17]. In North Carolina, caregivers are aged 60 (average), caring for a parent aged about 74 [18]. Caregivers give their money and time in order to provide for family members, with 70% and 71% of caregivers changing their work schedules and using their own money to provide care, respectively [18]. Informal caregivers suffer adverse mental health effects, with 63% citing experience with emotional stress and 58% finding it hard to get enough rest at night [18]. These effects are pre-pandemic and have been heightened by COVID-19 [19].

Women caregivers, especially BIPOC women, are the most negatively affected by the pandemic. Women represent 54.1% and 50.3% of home health aides and nursing

assistants, respectively [20]. Nationally, 30.3% of women of color in the health care and social assistance sectors have filed unemployment claims since the pandemic began [20]. Large unemployment for women of color is devastating; 67.5% of Black mothers and 41.4% of Latinx women are the sole breadwinners for their families [20]. With risk of job loss, risk of infection, and loved ones at home to care for, women caregivers are struggling to keep their families afloat.

Female caregivers experience further difficulty as they are often socially or culturally expected to provide care for their loved ones. On one hand, these women are discouraged from taking time off work for fear of negative perceptions about their commitment to their job [20]. At the same time, the work and pay received (minority women more often work in COVID-19-prone essential work fields) is essential for caregiving costs, such as medical expenses and child care.

Recommendations

Provide Long-term Care Residents With Virtual Visits

Prolonged social isolation and quarantine in LTSS facilities, although necessary, may lead to negative mental health effects for LTSS residents. NCDHHS should mandate that all LTSS facilities and nursing homes provide the means for each resident to hold “virtual visits” with loved ones. The state should work with families to provide the necessary devices and broadband for LTSS residents, providing funding if possible. Money for adequate broadband and laptops may not be readily available for all LTSS facilities. Some families may be able to provide devices for their loved ones, lessening the financial burden on the institutions. While visitation restrictions have recently been loosened in North Carolina for LTSS facilities, enhancing the capacity to do virtual visits will help facilities keep cases low and make it easier to pivot to 100% virtual visitation should there be a dangerous uptick in cases [21, 22].

Increased Support for BIPOC-majority LTSS Facilities Rated 3 Stars and Under

Long-term care facilities with majority-BIPOC residents should receive increased financial and infection prevention support from the State of North Carolina. Because Black- and Latinx-majority nursing homes are two times more likely to experience an outbreak than white-majority nursing homes, the state should divert funds to preventing further spread in BIPOC-majority LTSS facilities [9]. While biweekly staff testing was mandated by the Secretary of NCDHHS into fall 2020, this needs regular evaluation. Increased access to PPE should be implemented and supported without gaps, which lead to spread. Funding is a limitation for this recommendation. However, nursing homes account for approximately 40% of US deaths, therefore, decreasing the viral transmission and death toll in LTSS facilities should be a state priority [7].

Provide Formal and Informal Caregivers With Protections

Formal and informal caregivers require significant support and protections from the state, namely paid leave and adequate health insurance coverage. Formal caregivers share the risk of infection and death alongside residents at facilities. If workers do fall ill, financial support like paid leave should be made available so that workers can still provide for their families. Informal caregivers should be provided with necessary protections as well. If informal caregivers hold positions in high-risk, essential jobs, paid leave and adequate health insurance should be made available through employers. If informal caregivers themselves are sick or they need to take time off to care for a loved one, they should not be penalized for missing work. North Carolina can implement informal caregiver protections to mitigate the harm of decreased pay and layoffs due to missed work.

Facilities and caregivers functioning in the LTSS sector

are caring for the most vulnerable in our state and across the country. Yet, they are often at high risk themselves from COVID-19. The state should focus testing, tracing, protective equipment provision, and forthcoming vaccinations on long-term care settings and long-term care workers. Further protections should be provided to long-term care workers and family members alike who provide care to older adults and disabled individuals in our communities. NCMJ

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