

A Consumer Driven Research Agenda to Study Nursing Homes/Assisted Living Facilities and the COVID-19 Pandemic

By Alice H. Hedt, MUA March 2021

One year ago, long term care advocates were propelled into new arenas of activism as they witnessed the pandemic impacts on America's 2.4 million people in nursing homes and assisted living. Worried about the effects of the lockdown, the advocates could never have imagined a full year of isolation and the suffering that resulted. They were, however, intensely aware that residents would bear the consequences of low staffing, poor infection control, inadequate RN coverage and limited person-directed care that had not been addressed for years by the regulatory or quality improvement systems.

In the midst of the initial 2020 outbreak, advocates identified key areas needed for research, knowing that significant changes in the long term care system would be needed so that future pandemics would not have the same consequences on residents. There was great urgency in the discussion of needed research, as advocates heard the frustrated voices of residents and their families frantically worried as visitation was suspended.

Now is the time for researchers to study unaddressed topics so the difficult lessons of COVID-19 can be used to inform policy issues and guide providers in decision-making about care. While important research has been conducted (C. Harrington, Y. Li, S. Slocum, A. Montgomery and others), much more is needed. The future of long term care in this country should be shaped by the experiences of residents, their families and staff including changes that need to be made in emergency planning, the reporting of pandemic information, the relationship of long term care to public health, the impacts of isolation on residents, and the provision of care.

ADVOCATES SEEK CONSUMER DRIVEN RESEARCH

Advocates* identified four major research areas based on what they heard from consumers and witnessed themselves prior to and during the early months of the pandemic:

- Factors that impacted resident and staff infection and death rates;
- Federal and state government policies;
- Facility specific policies and procedures in response to COVID-19;
- The resident experience including impacts on family, friends, and staff.

This consumer-driven research could influence policy makers and providers at every level in short-term and long term decisions. The advocates agreed research needs to be quantitative and qualitative, reflecting the consumer perspective. The characteristics of facility hot spots

and exemplary performers need to be identified. Widespread variation in policies and practices across states provides an opportunity to learn the impacts of state, local and federal government actions. Advocates strongly urge that research include assisted living facilities where over 1.2 million people reside who are often ignored because data is difficult to obtain. The pandemic impact on [residents with dementia](#) is critical since they make up more than 40% of the resident population (nursing homes – 48%, assisted living – 42%).

Listed below are components identified by the advocates in the four areas of research.

I. Major factors that impact resident and staff infection and death rates:

- Staffing including RNs and total nursing staff levels; reliance on part time and temporary staff; staff working multiple jobs; qualifications and role of infection preventionist; role and responsibilities of RNs, physicians, medical directors, social workers, therapists and others
- Pre-outbreak planning and regular training provided to staff on emergency preparedness and infection control
- Quality of the facility including: ratings on nursing home compare, complaints, deficiencies; quality measures; prior infection control, sanitation, and emergency preparedness violations; special focus facility designation
- Facility focus on person-centered care or culture change guidelines
- Residents – age, chronic conditions, race, short or long stay, mental or development disabilities and other characteristics
- Facility characteristics - ownership, profit or non-profit, chains or non-chains, location (rural, urban, suburban, inner city); number of beds; occupancy rate; part of multi-level facility or campus; payer sources, including Medicare and Medicaid
- Facility design and size - residents per room, availability of isolation rooms and wings, age of building; open spaces for social distancing, outdoor spaces; use of multiple small buildings (i.e., cottages), high rise buildings
- Facility financial, ownership, and lending practices that limit staffing and direct care resources by directing funds to management companies; related-party companies; lease arrangements, administrative costs, and profits
- Prior state regulatory oversight and enforcement practices, including no-harm citations for deficiencies

II. Federal and state government COVID-19 policies and practices:

- Facilities required to accept patients from hospitals without prior test results; not placing a hold on admissions for COVID-19 and non-COVID-19 residents
- Lack of criteria for COVID-19 units or COVID-19 facilities; allowing facilities with low quality ratings and a history of neglect and abuse become COVID facilities
- Implementing no visitation policies on family, friends and long term care ombudsmen

- Suspending regular state survey inspections, complaint investigations, monitoring, and enforcement of regulatory requirements including staffing standards and nurse aid training
- Interventions of survey teams/public health focused on infection control
- Establishing “temporary staff” criteria with less than 10 hours of training
- Availability and use of local hospital and health department staff, and "strike/resource teams" for urgent situations
- Integration of assisted living and nursing homes in local, state and national emergency preparedness plans
- Not prioritizing facilities for the supply and distribution of PPEs and tests
- Not requiring all nursing home residents and staff to be tested until June 1st
- Not requiring facilities to publicly report resident/staff infection and death rates until June 1st; suspending regular nursing home reporting of staffing data
- Political pressures and campaign contributions from industry to influence policy decisions such as immunity and distribution of government payments to providers
- Granting facilities legal immunity from prosecution related to COVID19

III. Facility COVID-19 policies and practices:

- Co-horting COVID-19 and non-COVID-19 residents; creating specific COVID units
- Hospital admissions of COVID-19 positive residents
- Discharges to hospitals and COVID specific facilities; deaths of residents sent to hospitals
- Availability and use of PPE, masks, sanitizers (when started, frequency, effectiveness) for staff/residents
- Testing of staff/residents (when started, frequency, effectiveness)
- Extent and type of staff education on infection control, hand washing, use of PPE
- Transparency in reporting COVID infections and deaths to staff, families, health departments, and government
- Use of ombudsman during pandemic
- Practices to support residents with dementia
- Practices to facilitate communication between residents and family/friends; residents and other residents; staff and family including telecommunication and activities
- Use of person centered care planning process prior to and during pandemic
- Care practices during the pandemic that impacted outcomes such as pressure sores, other infections, dehydration, weight loss, falls, non COVID deaths, use of antipsychotics
- Extent and type of abuse in facilities during pandemic (by staff or residents)
- Incentives to address staff stability (adding hours to eliminate staff working in multiple sites, overtime rates, bonuses, access to counseling, morale builders
- Impact of access to health insurance, sick leave, hazard pay
- Impact of staff attendance, turnover rates, resignations, morale

- Use of extra federal or state emergency funding for direct care, staffing, PPEs, testing, hazard or sick leave pay, management fees, leases, third party payers, payments to owners and shareholders

IV. The resident experience, and impacts on family, friends and staff:

- Changes in direct care including bathing, dressing, toileting, transferring, walking, turning, receiving treatments and medications, nutrition
- Resident pain, distress, loneliness, depression, resiliency
- Resident transfer trauma (different room, facility, or multiple transfers)
- Abuse (verbal, physical, etc.) and neglect (pressure sores, dehydration, weight loss, etc.)
- Increased disorientation for all residents including those with dementia
- Loss of rights (i.e., access to visitors, protections against discharge)
- Changes in quality of life (i.e., group activities and meals, access out room or to outdoors)
- Honoring end of life wishes; hospice and palliative care; compassionate care visits
- Resident perspectives on actions that made or could have made the pandemic more tolerable (i.e., laptops, resident involvement in facility decision making, personal access to sanitizer)
- Family perspectives on actions that made or could have made the pandemic more tolerable (i.e., frequent updates from facility, on-line family council meetings, care plan meetings)
- Staff perspectives on actions that made or could have made the pandemic more tolerable (i.e., use of consistent staffing, training, increased pay)

THE CONSUMER MESSAGE DURING COVID – 19

The topics identified above were articulated by residents themselves, consumers and their advocates who became more desperate over time – pointing out residents’ decreased will to live, families’ fears of what was happening with reduced staff and huge medical challenges, and the frustration of not having access to information about how widely the new virus had penetrated facilities. Consumers were stunned that early in the pandemic residents and staff made up [42% of all deaths](#) with some states [reporting rates as high as 60 to 80 percent](#). Increasingly consumers saw the wide spread of COVID in nursing homes and assisted living as [“a national disgrace”](#). In early 2021, residents and families learned that their deepest fears had played out as long term care residents made up over 1/3 of more than half a million deaths.

A major component of consumer frustration was that well-established communication links and protections disappeared with the lockdown of facilities. Families and friends could no longer

visit, resulting in the loss of social interaction, compassionate touch, and the hands-on nurturing provided by many who helped feed and care for their residents. People with dementia did not understand why their loved ones disappeared. More than 7,000 volunteer and employed certified ombudsmen no longer entered facilities to answer resident questions and address grievances. Annual nursing home surveys and assisted living inspections were suspended when the federal government directed state regulatory agencies to focus on infection control and complaints, typically using telecommunication rather than on-site visits. Consumers asked, “What is going on in facilities when families, friends, ombudsmen and regulators are gone?” In the absence of information, consumers feared and too often experienced the worst.

Simultaneously, the onset of COVID-19 shifted the purpose of nursing homes. When the Nursing Home Reform Law was passed in 1987, passionate advocates and dedicated care providers strove to create “home” for residents based on the law’s establishment of specific resident rights and the concept that quality of life was equally important to quality of care. Suddenly in response to COVID-19, with limited if any input from advocates, decisions were made on national, state and community levels that transformed peoples’ homes in nursing homes into step-down units for hospitals to discharge patients who might or might not have the virus. Some residents were forced to move - leaving friends, routines and familiar care givers, so facilities could become COVID units. Nursing homes that struggled without enough direct care staff and inadequate RN coverage prior to the pandemic were propelled into a new arena of caring for patients with unclear medical diagnoses during a fast spreading pandemic.

Some facilities were successful in limiting the impact of this horrifying virus with no or few coronavirus infections among staff or residents. They established new compassionate routines to enhance resident/staff interactions while simultaneously addressing infection control and providing routine person centered care. Some facilities were transparent in regular communications about the extent of coronavirus and the facility’s response.

Other facilities lost the coronavirus battle with the rapid spread of COVID cases and deaths in both staff and residents. These “hot spots” frightened consumers who worried about both the virus and about receiving basic care. The [racial disparities](#) of the pandemic appeared in facilities that had increased likelihood of COVID-19 cases if the residents were brown and black. Consumers are not naive. Consumers understood that long term care residents are medically fragile and that some would die. But consumers did not understand why facilities did not have PPE, tests, and early infection control training. Residents worried that the staff who care for them, who were their safety net and friends, were at risk as some needed to work multiple jobs and others had too little PPE, sick leave or training.

Consumer advocates, including ombudsmen, watched the unfolding COVID-19 pandemic shatter the connections between residents and families. While attempting to explain the new

temporary regulations established by CMS to consumers, advocates were deeply concerned about [poor infection control](#) identified by regulators in the last three years in 75% of nursing homes that did not necessarily result in sanctions. They worried that the government never implemented minimum [nurse staffing requirements](#) after research established that without at least 4.1 hours of direct nursing care per day, nursing homes could not prevent pressure sores, weight loss, unnecessary hospitalizations and loss of functional ability and enable residents to “attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident” as required by the law. [42 U.S. Code § 1395i-3(b) (2)]

SUMMARY

Consumer driven research can point the way to changes needed in our long term care system to stem the spread of COVID-19 and influence planning for future pandemics and emergencies. It can save lives and lay the foundation to reimagine what long term care should look like. What regulatory changes are needed to address virus spread? How do we need to redesign buildings (i.e., Greenhouse and small home models, more outdoor space)? How should home and community based services be expanded with more capacity to care for medically fragile adults? What practices in other countries could improve our current system? Should the Medicare and Medicaid reimbursement system, the largest financier of nursing home care, be overhauled to create incentives that provide consumers more choice and better quality?

Now is the time for researchers to examine the consumer driven issues that have yet to be addressed. Advocates believe that research driven by consumer needs and experiences is essential to answering the above questions and creating solutions so that the suffering, isolation, and death experienced this past year can be addressed for all who need long term care in the future.

***Participants identifying consumer driven research topics:**

California Advocates for Nursing Home Reform: Tony Chicotel, Staff Attorney; Michael Connors, Long Term Care Advocate; Janet Wells, Public Policy Consultant

Center for Medicare Advocacy: Toby Edelman, Senior Policy Attorney

Justice in Aging: Eric Carlson, Directing Attorney

Long Term Care Community Coalition: Richard Mollot, Executive Director

Michigan Elder Justice Initiative: Alison Hirschel, Managing Attorney

The National Consumer Voice for Quality Long Term Care: Sam Brooks, Program Manager; Robyn Grant, Director of Public Policy & Advocacy; Lori Smetanka, Executive Director

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The author, Alice H. Hedt, convened the advocates to identify needed research and specific aspects of the pandemic. She is available to discuss this article at aliceahh@gmail.com.