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The Intersections of Structural Racism and Ageism in the Time of COVID-19: A Call to Action for Gerontological Nursing Science

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Abstract

The health consequences of systemic racism and ageism have received growing attention as the COVID-19 pandemic has illuminated long-standing inadequacies and injustices that are structurally engrained in our health systems. This State of the Science Commentary addresses the intersecting influences of systemic racism and ageism, and other 'isms' that conspire to create disparate health outcomes for older adults from historically excluded and marginalized backgrounds. We focus specifically on the long-term care (LTC) sector as a representative microcosm of structural inequities, while recognizing that these unjust barriers to health are widespread, endemic, and pervasive. We present a call to action for gerontological nursing science to engage deeply and robustly in these realities, and the ethical and scientific imperative they present to ensure that *all* older people encounter just conditions for maximizing their health and wellbeing.

On February 29, 2020 the first American novel Coronavirus-19 (COVID-19)-related death was confirmed. Shortly thereafter, an outbreak at a nearby long term care (LTC) community reported over 50 residents and staff reporting respiratory and flu-like symptoms—some severe. These early stages of the United States (US) COVID-19 pandemic situated early framing in public discourse of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) as a concern that affected predominantly "elderly people with health problems and other problems" (Bella, 2020).

Since February of 2020, more than 595,000 Americans have died from complications related to COVID-19 infections (CDC, 2021a). Where age related data was available, adults aged

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65 and older have accounted for 80% of these deaths (CDC, 2021b) with approximately 32% of affected persons residing in LTC communities (The New York Times, 2021). Unsurprisingly, essential workers, or the necessary clinicians and staff caring for these residents, are at risk for both infection and infection-related complications including death. Between May 25 and November 22, 2020, 275,373 COVID-19 infections were documented in LTC workers (Bagchi et al., 2021), and to-date, 1,969 LTC staff have died of COVID-19 related complications (CDC, 2021c). The COVID-19 pandemic has taken an incalculable toll on LTC residents, staff, and families; and presents an important opportunity to examine the social inequities and intolerance the pandemic exposed.

Fear and uncertainty surrounding the pandemic has been accompanied by heightened scrutiny of institutionalized and systemic racism, largely visible social inequities, and significant reductions of in-person contacts both inside and outside of care communities. Collectively, this public discourse and the incalculable loss of life and bereavement precipitated by the COVID-19 pandemic has brought light and renewed interest to oft neglected topics of central relevance to gerontological nursing including institutional and structural racism, ageism, classism, cisgenderism, homophobia, and transphobia. This state of the science commentary examines the intersecting influence of various harms and inequitable practices that prevent the optimization of health and reduce quality of life for LTC residents and their professional caregivers.

We focus our attention on LTC settings, encompassing skilled-nursing, nursing homes and assisted living facilities, which have well-documented and long-standing histories of racial segregation (Mack et al., 2020). These broader structural differences in care access, staff opportunities and treatment are exacerbated by disparities among historically excluded and marginalized populations including members of minoritized racial and ethnic groups and those who are socioeconomically disadvantaged or live in rural areas (Mor et al., 2004; Rivera-Hernandez et al., 2019). Differences in outcomes among non-white, socioeconomically disadvantaged, and rural LTC residents have been documented across a number of domains, including health, quality of life, and social engagement (Bowblis et al., 2013; Campbell et al., 2016; Li & Cai, 2014). We posit that gerontological nursing science has both a scientific and ethical imperative to critically evaluate the undercurrents of ‘isms’ that conspire to perpetuate health disparities among older adults. To achieve this, we review salient structural competencies and frameworks that can help us understand underlying causes driving systemic inequities and consider their relevance to interrelated challenges specific to the LTC workforce and surrounding care quality initiatives that demand attention to achieve gains in health equity and anti-racism in gerontological nursing care and science.

Structural Competencies and Frameworks

People with diverse identities provide and receive care in LTC settings. Everyone receiving care in LTC communities has a right to high quality care that is culturally responsive to one’s preferred language, diverse cultural beliefs, practices, and health literacy levels (USDHHS Office of Minority Health, 2018). Culturally responsive care is foundational to alleviating systematic biases that produce poorer care quality and outcomes among persons from historically excluded and marginalized identities. While individual–level care

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is important to this goal, understanding and addressing how health inequities are also structurally and systematically shaped through institutions and the social conditions that influence how health resources are accessed is equally necessary to improve health equity (Metzl & Hansen, 2014). Structural competency refers to the ability of health professionals to discern the influence of 'upstream' social determinants of health – the contexts in which people live and age – on health systems, clinical problems, and diseases. Efforts to address the consequences of racism and ageism in LTC necessitate a strong understanding of domains central to structural competence, including intersectionality, and access to research frameworks that facilitate their operationalization in research.

Intersectionality

The conceptual framework of intersectionality was introduced by Law Professor Kimberle Crenshaw more than thirty years ago in response to the complexity of antidiscrimination work which tends to focus on singular issues such as race or gender (1989). Rather, intersectionality focuses on examining multiple, interlocking systems of oppression and marginalization that impact and frame peoples' lives through the convergence of key social statuses such as age, race, ethnicity, gender identity, sexual orientation, and abilities (among other domains) within dominating systems (Crenshaw, 1991). Leveraging critical race and critical feminist theory, which focus on unequal distribution of power, social and economic opportunity, Crenshaw argued that antidiscrimination laws and policies would have the greatest effect by focusing on creating inclusive environments for the most disadvantaged —those holding multiple marginalized identities. Intersectional approaches emphasize that categories of difference, particularly social categories throughout history align with racism, colonialism, patriarchy, and capitalism (Ferrer et al., 2017). Intersectionality provides insight into how to examine the interplay between life experiences that may include caregiving, education, employment, housing, immigration or migration status, poverty, and identity, as well as how these experiences fall within larger systems of oppression (Ferrer et al., 2017). While under-utilized in gerontological nursing science, intersectionality offers an approach for addressing inequities and is responsive to the complex realities of identities and social exposures that intersect, interact, and compound one another to shape health disparities (Holman et al., 2020). These disparities often influence whether an individual enters a LTC setting or not and what type of environment they enter, and also influence broader structures and systems, such as decisions to make LTC services available in rural or socioeconomically disadvantaged neighborhoods.

Intersectionality: The Lived Experience

LTC settings have traditionally catered to a myopic, stereotypical idea of the older adult —that is the U.S. born, middle-class, white older adult—particularly in their décor and culinary and therapeutic programming (Nichols, 2020). Minoritized older adults who enter LTC communities bring their identities and lifetime of experiences with oppressive systems with them. These experiences can significantly increase stress and negative health outcomes for marginalized populations and complicate their transitions into yet another overtly structured living environment that rarely recognizes or encourages differences (Paradies et al., 2015). For example, most LTC settings have admissions processes and paperwork that do not recognize the various gender and sexual identities that a person may bring with them

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(Caceres, 2019). Individuals who identify as lesbian, gay, bisexual, transgender, or queer/questioning (LGBTQ) encounter denial of care community admission, maltreatment by staff, isolation from other residents, and discrimination by residents has led many LGBTQ older adults to conceal their sexual identities after having been open in the community (Mahieu et al., 2019, National Senior Citizens Law Center, 2010). Long-term care communities thus becomes the driver of oppression and discrimination towards persons of different backgrounds or family structures.

Racism, classism, and other forms of discrimination and oppression remain ongoing, understudied concerns in LTC communities. Advances that may begin to address these challenges will benefit from approaches that leverage intersectional and focus on increased autonomy by engaging the individual in their own care such as person-centered and/or person-directed care (Lepore et al., 2018). Common examples of such efforts in LTC include the Eden alternative (The Eden Alternative, 2016), The Green House Project (The Green House Project, 2021), and Age-Friendly Health systems (Institute for Healthcare Improvement, 2021) which encourage culturally responsive care approaches and address ageism and the four M's, medications, mobility, mentation, and what matters. Each of these care models also reflects an attempt to decrease the power structures in LTC. Unfortunately, these models of care do not purposefully address the racism, cisgenderism (systems that deny or disparages self-identity of gender) and heteronormativity (behavior that ignore, disparage, or pathologize LGBTQ populations) that is often pervasive in LTC. Further, the risk of having ones concealed sexual identity outed followed by discrimination may limit studies that engage LGBTQ seniors residing in LTC communities.

Members of minoritized racial and ethnic groups face similar challenges. Black older adults who make up approximately 14% of the LTC populations commonly receive care in racially segregated communities with poorer quality care (Harris-Koetin et al., 2019; Mack et al., 2020). For many of these individuals, this reflects an extension of life-long systematic and structural racism that has had a dramatic impact on health access and wellbeing such as the practice or redlining, which was orchestrated by municipal laws and regulations that legalized institutionalized racial segregation, including in healthcare delivery. As a result, many Black adults over 65 did not experience equitable access to healthcare services for at least the first decade of their lives (History.com Editors, 2021). During the COVID-19 pandemic, COVID related deaths among nursing residents disproportionately affected care communities servicing more Black and Latinx residents (Chidambaram et al., 2020). Collectively it is vital that gerontological nursing recognizes the ways in which these seemingly distinct phenomena have share determinants; and the impact of life-course stressors and discrimination on late-life care access, utilization, and outcomes.

Creating an environment that celebrates diversity while addressing sources of discrimination and historical trauma in interpersonal interactions holds potential to maximize resident safety and well-being. Such efforts are critical given the feelings of vulnerability and lack of freedom and movement that LTC residents describe, with LTC environments even described by some residents as feeling like prisons or extensions of plantations (Caspari et al., 2018). To feel entrapped in an environment and then exposed to discrimination both perpetuates and reactivates trauma in late-life.

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Gerontological nursing science is well poised to investigate approaches to safe and inclusive systems and environments that meet the needs of older adults who identify as LGBTQ, disabled, and/or as a member of a minoritized racial/ethnic group. By identifying and evaluating how organizations are facilitating the inclusion of the most marginalized, we can begin to create policies that increase equitable care accountability. In efforts to promote culturally appropriate and responsive care for older adults in LTC settings, intersectional approaches are essential to recognizing, and being responsive to older adults intersecting identities as well as their life experience and how this has shaped their interactions with dominating systems.

Intersectional Research Frameworks

Gerontological nursing research that addresses resident's perspectives and experiences regarding socioeconomic background, gender identity, culture, race and ethnicity, and sexual identity is urgently needed to inform our understanding of sources and outcomes of discrimination, in addition to their mechanisms. This includes examining how reimbursement, staffing patterns, nursing leadership, and other factors may drive disparities in quality of care, quality of life, wellbeing, and health outcomes; as well as investigation of environments that successfully foster inclusive care (Mahieu & Gastmans, 2015). Research frameworks exist that can facilitate adoption of intersectional approaches in these efforts, including the National Institute on Aging's Health Disparities Research Framework (Hill et al., 2015). The framework highlights four domains for evaluating determinants of health disparities that operate across the life-course including environmental, sociocultural, behavioral, and biological and three levels of analysis. Much of the needed research on health disparities within LTC could emphasize multilevel environmental determinants. The framework provides a structure for systematic investigation into differences in quality of life, pain management, disease progression, and treatment practices to generate best practice evidence of the difference equitable and inclusive care makes. Such lines of inquiry may emphasize micro (facility), meso (chain), or macro (state/regional/national) levels of analysis to identify any differential care practices that may affect the target populations. There are also opportunities to consider the influence of socioeconomic factors on LTC admissions, lengths of stay, and care trajectories, or similarly the influence of geographical and political factors on care access, delivery and outcomes.

Beyond frameworks, novel analytic approaches such as multilevel analysis of individual heterogeneity and discriminatory accuracy (MAIHDA) are well suited to intersectional frameworks and research questions (Merlo, 2018). MAIHDA represents a reorganization of concepts to facilitate more precise estimates of both the distribution and determinants of individual outcomes and exposures by estimating both differences between group averages as well as individual heterogeneity around such averages. Applied through an intersectional framework, the MAIHDA produces estimates of stratum-specific total interaction effects based on dimensions of specified intersectional strata; enabling better evaluation of multiple points of intersection across axes of marginalization. Careful attention to and investigation of descriptive features of health differences across sub-populations is also recommended in the evaluation of health disparities (Ward et al., 2019). The range of questions around the relationships between social, economic, organizational, and legal factors that promote

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equitable care and health outcomes requires a range of diverse perspectives—including various study designs and theoretical frameworks to move this work forward. A critical part of this work will be considering how to begin to address long-standing direct-care workforce issues that affect patient care outcomes.

The Long-term Care Workforce

While numerous studies have examined relationships among staffing, quality of care, and resident outcomes (Harrington et al., 2020), fewer studies have examined the health and wellbeing of LTC workers, which as a large, vulnerable population merit attention in their own right. An important target for intersectional research attentive to the diversity of the staff in the LTC sector is occupational health, with worker wellbeing a central component. Occupational health for nursing assistants (NAs), who comprise a third of the LTC workforce and provide 80% of direct care, is particularly urgent (Campbell, 2017; Paraprofessional Healthcare Institute, 2011)

NAs represent a disenfranchised workforce, with few routes for advancement and considerable risk in advocating for an improved work environment. NAs may face limited career options, with half possessing a high school degree or less (Campbell, 2017)—a result of long-standing inequities in educational systems which often fall along socioeconomic and racial fault lines. NAs are predominantly women, low wage earners, and many identifying as members of minoritized groups with 36% identifying as Black or African American, 11% as Hispanic or Latinx, and 20% as immigrants (Campbell, 2017). Yet research on NAs and their occupational health rarely applies an equity lens. Limited evidence indicates there may be disparities in job strain, hours, and income between white and non-white LTC workers (Hurtado et al., 2012) and that low socioeconomic status may leave NAs particularly vulnerable when facing workplace injuries (Haas et al., 2018).

Overall, NAs face major impediments to achieving health due both to working conditions and challenges both challenges many NAs face in their lives outside work including chronic health conditions, multiple caregiving roles, and financial stress (DePasquale et al., 2016; Haas et al., 2018). These challenges are exacerbated by staffing shortages, high turnover rates, low and disparate pay, minimal benefits and protections, and dangerous work environments (Geng et al., 2019; Walton & Rogers, 2017). NAs of color are also exposed to racial discrimination by residents, family members, and other staff in the form of racial slurs and false accusations, (Ejaz et al., 2011; Travers et al., 2020). NAs identifying as immigrants have reported feeling a lack of respect from residents and family (Sloane et al., 2010). Angel Jackson, a nursing assistant and panelist in the 2020 Annual Summit of the Advancing Excellence in Long-Term Care Collaborative, described the impact of workplace discrimination (Jackson, 2020):

> “Sometimes it feels like you know it brings down our self-esteem pretty much like okay this is how we gotta do and this is how we have to be and sometimes it makes us feel like you know maybe we can’t come up to the level of our other you know coworkers.”

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Additionally, a lack of organizational response, or even the practice of coaching staff to ignore discrimination, may perpetuate a hostile and traumatizing work environment that may contribute to negative mental health outcomes and a desire to leave the LTC workforce community (Travers et al., 2020; Zhang et al 2014). A workplace that has normalized discrimination ignores the extensive body of research demonstrating its relationship to heightened stress responses and poor health outcomes (Pascoe & Smart Richman, 2009).

The persistent lack of investment in NAs also signals a devaluation of their work, with the majority of LTC settings not providing incentives for NA education and downward trends in internal training programs (Berridge et al., 2018). The lack of investment in NAs is not equally distributed, with white NAs experiencing some buffering compared to counterparts in wages, benefits, and work conditions (Price-Glynn & Rakovski, 2012) and perceived lack of promotional pathways for NAs of color given predominance of white staff in senior level positions (Adams, 2020). In the aforementioned 2020 Summit, panelist Angel Jackson described unequal opportunities to become a lead NA and panelist Marvell Adams elaborated on how a lack of diversity early in the pipeline leads to a lack of diversity in senior positions, and described the phenomenon where mentors are more likely to select mentees with whom they share characteristics. Organization-level discriminatory practices—though less visible than racial slurs—are still felt deeply by those affected, thus reinforcing the need for structural competencies inclusive of the needs of direct care staff.

Expanded research focused on maximizing NA occupational health is urgently needed, with proposed solutions including a higher minimum wage, wage pass-through programs, minimum staffing levels, elimination of lockout periods for NA training, robust educational programs with career ladder options, and greater adoption of staff empowerment practices (Harrington et al., 2020; McGilton et al., 2016). There remains is untapped opportunity to understand NA goals and needs to design optimal educational programs.

In establishing a greater body of research on NA occupational health, careful consideration to markers of employee health must be given, as these may include physical and psychological wellbeing, job satisfaction, turnover, retention, absenteeism, injury and illness rates, and job hazard rates. Finally, attention to sources of discrimination, at interpersonal, organizational, and systemic levels are needed, with solutions for addressing pervasive racial discrimination required. This is in addition to the need for grief and mental health services in light of the trauma of the COVID-19 pandemic. Though NA wellbeing is generally tied to resident outcomes, NAs should be provided opportunity, respect, and an environment free from discrimination regardless of impact on resident outcomes and improved health and wellbeing.

Culturally Competent Care and Quality Initiatives

Quality initiatives in LTC have largely centered on regulations, reporting, and monitoring requirements set forth by the Centers for Medicare & Medicaid Services (CMS) largely centered around the Minimal Data Set (MDS) as the primary tool for collecting data on the health status of LTC residents (Saliba & Buchanan, 2012). Unfortunately, quality issues surrounding diversity, inclusion, and disparities in care among minoritized populations has

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been a low priority in LTC communities. The CMS recently announced plans to increase equitable care delivery to beneficiaries by prioritizing the collection and accessibility of patient-level data on race, ethnicity, language, sexual orientation, gender identity, disability status, and geographic location as well as increased attention to workforce needs (Centers for Medicare & Medicaid Services, 2021). LTC communities receiving CMS funding are required to meet an extensive list of requirements regarding how care is to be delivered. Within these requirements are rules emphasizing residents' rights to be treated with dignity and respect and "in an environment that promotes maintenance or enhancement of his or her quality of life, recognizing each resident's individuality" (Electronic Code of Federal Regulations, 2021). As organizations must deliver care that amplifies the values and needs of the person; they are essentially responsible for delivering culturally responsive care, yet continue to lack adequate resources, guidance, training, or support to achieve these goals.

The National Standards for Culturally and Linguistically Appropriate Services (CLAS) recently outlined 15 standards detailing steps healthcare organizations can take to strengthen equity through responsiveness to the unique attributes of the communities they serve (U.S. Department of Health and Human Services Office of Minority Health, 2018). This responsiveness is reflected in health education materials and services being available in the languages spoken by community members, diverse leadership that promotes and is accountable for culturally and linguistically appropriate care, and equity focused quality improvement goals that are openly communicated and built into organizational policies and procedures. In LTC settings, limited resources for the collection and analysis of data relevant to CLAS standards serves as a limitation to their implementation (Ng et al, 2017). Nevertheless, LTC organizations have an important responsibility to examine which CLAS standards are currently being met within their institutions and which may require additional attention. A formal organization equity report may be one of the first steps in this directions.

Similar to quality reports organizations already generate, an equity report provides data-based information about care delivery based on various social determinants of health or their indicators, such as race, ethnicity, insurance type, and primary language. In particular, organizations serving a perceivably homogenous population may have the most to gain by assessing if the population currently served is truly representative of the community the organization is seated in and how presumptions around heteronormativity, cisgenderism, racism, and class may influence organizational practices, policies, and culture. Describing intragroup differences that may be present and examining presumed group values can provide important contextual information about care access, utilization, and delivery.

Weinick, Flaherty, and Bristol (2008) provide a detailed guide for developing equity reports within hospital systems that may be adapted to the LTC setting. Key questions to consider early in the assessment process are 1) What data is already being collected by the organization about the racial, ethnic, and sexual/ gender minorities currently served and LTC staff, 2) Which populations are currently served by the organization, 3) Which staff to involve in the equity report development process, 4) What resources are needed (access to data, staff time, etc), and 5) What are the barriers that may prevent the completion of the report or addressing any concerns that the report may raise? Engaging the right stakeholders early in the equity report development processes increases the likelihood of collecting timely

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and accurate information, and strengthening relevance, sustainability, and accountability to equity related goals and benchmarks.

Future Directions

As the number of older adults from diverse backgrounds and identities using LTC services continues to rise in accordance with demographic trends and potential lack of access to community-based care alternatives, attention to sources of disparities in availability, quality of care, and delivery of person-centered care is urgently needed (Feng et al., 2011). LTC culture, environment, and interpersonal interactions may play an important, yet under recognized, role in shaping quality outcomes and equitable care delivery for diverse LTC residents. Inclusive, culturally responsive care that is attentive to structural competency and intersectionality aligns with central tenets of person-centered care and has the potential to reduce health disparities, thereby representing an urgent area for research and implementation of evidence based practice. Further, a robust, healthy workforce is central to the delivery of effective and equitable care. Attentiveness to the manner in which treatment of staff occurs, including the availability of career advancement opportunities, may bolster the LTC staff health and workplace retention. Organizational equity reporting inclusive of both staff and patient outcomes may be central to efforts to improve care for older adults and necessary supports for LTC community NAs. Gerontological nursing science is uniquely poised to lead efforts to identify, disambiguate, and intervene on the intersecting ‘isms’ that reinforce a reality of unequal care for older adults in LTC, and beyond; and the field must not delay in leading this charge.

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