


The COVID-19 Pandemic Reignites the Need for Person-Centered Gerontological Approach

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Abstract

The national response to the COVID-19 pandemic pressed gerontologists to reflect, redesign, and reform services supporting older adults. Efforts to isolate a peer cohort to stabilize and maintain a standard of health had adverse outcomes and added pressure conflicting with autonomy and individual desires. In this, person-centered care emerges as a meaningful archetype to address dignity and independence. This article presents views from academics and practitioners across an interdisciplinary spectrum, arising from a webinar hosted by Georgetown University Program in Aging & Health. A description of personhood as an extension of the humanities is followed by a robust discussion of safety and autonomy for older adults during the COVID-19 pandemic. We examine the necessary commute between critical gerontological theory and the practice of humanistic gerontology. Further, this article disentangles humanism and person-centered care to balance autonomy and safety for older adults in congregate living situations and focuses on specific populations: people with dementia and their care partners. Discussion on the importance of person-centered policy development in a public health pandemic is also explored. The article concludes with a call to action for the adoption of a comprehensive person-centered care model across the fields of gerontology and geriatric medicine.

Keywords

COVID-19, humanities and arts, person centered care, person-centeredness, autonomy, long-term care, policy, public health emergency

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As of August 2020 to present, according to the [Centers for Disease Control and Prevention, \(2020\)](#), eight out of 10 COVID-19 related deaths reported in the United States were in the population of adults 65 and older ([Centers for Disease Control and Prevention, 2020](#)). Older adults, predominantly those who are comorbid, experienced a range of adverse outcomes due to COVID-19 and were more likely to be hospitalized ([Garg et al., 2020](#); [Shah et al., 2020](#)). As of November 2020, 40% of all COVID-19 related deaths occurred in residents of long-term care settings ([Chidambaram et al., 2020](#); [Kaiser Family Foundation, 2021](#)). Weekly death averages continue to fall attributed to vaccinations among older adults ([Ladyzhets, 2021](#)). People living with dementia were at increased risk of contracting COVID-19 and

experienced worse outcomes ([Wang et al., 2021](#)). This group accounted for 44.6% of the COVID-19 deaths among Medicare Fee for Service (FFS) beneficiaries ([Lamont et al., 2021](#)). Responses from health and regulatory agencies included restrictive measures and policy interventions placed on older adults to reduce the risk of infection and death.

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The COVID-19 pandemic not only challenged those in the fields of healthcare and policy but pushed the field of gerontology to consider how safety and autonomy are prioritized for older adults during periods of emergency. In times of crisis, efforts to balance safety and autonomy may be at odds with the needs and/or wants of the older adult, pressing those of us in the field of gerontology to question how we uphold the values of autonomy while mitigating risk during unprecedented events. Further, the COVID-19 pandemic illuminated the need to disentangle how or if current gerontological theory benefits or hinders us as we address such issues of personhood and autonomy while in crisis. In addressing this dilemma, we find that an added demand for humanism emerges, casting a significant light on person-centered care.

To consider these issues, on April 21, 2020, the Georgetown University Aging & Health Program hosted a webinar on COVID-19 and older adults featuring the voices of academics, practitioners, representatives from local aging service organizations, as well as older adults from the community. Georgetown offers a master's degree in Aging and Health through the Graduate School of Arts and Sciences. The resulting disquiet from our discussions during and after the webinar was illuminating as it focused on the balance between risk mitigation and safety versus older adults' desires for autonomy and dignity. In this article, we draw on our observations and the current literature to examine how we as a nation have responded to older adults' needs. We then consider how a person-centered gerontological perspective offers positive implications for the future of gerontology and geriatric medicine.

Background

Humanism Operationalizes Person-Centered Care

From ancient times to the present day, humanism has influenced medicine and health care as a means of honoring personhood (Cole et al., 2010). In its contemporary form, the humanities provide the framework for interdisciplinary studies to address complex problems. This approach recognizes that knowledge of human beings is not complete unless it encompasses the preferences and life experiences of the individuals being studied (Taylor, 1979). The force of humanism as a mechanism for balancing autonomy and safety, with its focus on honoring personhood, leads us to consider its "offshoot"—person-centered care. As an operationalization of humanism, person-centered care provides a critical framework through which gerontologists can balance risk while fully supporting autonomy and dignity.

A person-centered approach to balancing autonomy and risk ensures the identification and inclusion of a person's needs and wants to find the best solution. Person-centered care starts with a focus on the individual and the need for individual responses (Fazio et al., 2018) and is deeply rooted in humanism. Rogers (1961), a founder of humanistic

psychology, espoused person-centered therapy as a holistic approach for the treatment of his patients. He recognized the importance of combining the person's subjective experience with his or her need to self-actualize. Thus, person-centered care guides care partners away from undifferentiated approaches as applied to all individuals and balances autonomy and risk to ensure the inclusion of a person's needs and wants. Person-centered care does not dismiss risk, but it addresses it at the individual level, leading with autonomy rather than risk reduction.

The 2001 Institute of Medicine report, "Crossing the Quality Chasm," shed further light on the need for individuals to be active participants in their care, considering preferences, values, and goals (Institute of Medicine, 2001). The report stressed focusing on person-centered care by placing the needs of the individual at the center of these healthcare reform debates; further, it accentuated a focus on the care of the person rather than the "person to the care" (Institute of Medicine, 2001).

Importance of Safety and Autonomy

The number one issue identified during the webinar on COVID-19 and older adults was the extreme emphasis on the need for safety and the subsequent actions taken to keep older adults safe during the pandemic. Unfortunately, these responses erred toward practices and policies based on chronological age as the primary factor and questionably over-emphasized safety at the expense of autonomy for all older adults.

How might we differently approach this imbalance? In considering the balance of safety and autonomy, we fear that honoring personhood has been highly lacking during this time of COVID-19. An example is apparent in the prevalent use of the phrase "Boomer Remover" (in reference to COVID and other ageist comments in public media). Is this evidence that our loftiest goals to reframe aging have all been thwarted? Is it truly "an abundance of caution" that leads us to focus on safety-first approaches throughout the national lockdown that has inordinately affected older adults? Or has the pandemic response enabled ageism and the loss of the civil and human rights of older adults beyond reasonable due process?

Achieving a Balance of Honoring Autonomy While Reducing Risk

We advocate for an approach that balances autonomy and risk. Figure 1 illustrates this balance with a scale anchoring safety on one end and autonomy on the other. We propose that balance can be achieved by using person-centered principles as the means of honoring autonomy while reducing risk. A concrete example would be the development of innovations in programming in congregate living communities to support older adults who need to socialize safely while staying within the requirements of public health guidelines. As the reader



Figure 1. Vision for humanistic person-centered gerontological model.

will see, we strive to connect these innovations with their roots in humanism and, consequently, person-centered care. Additionally, we consider how gerontology can promote these values for all older adults. Finally, we link these innovations with theories of political economy, considering public health policies that are often created with the big picture in mind rather than the individual's experience (Minkler & Estes, 1991).

Humanistic, person-centered approaches benefit all older adults and are not limited to those in senior living communities. These approaches are also applicable to the support of people living with chronic conditions such as dementia. Although a person-centered lens in gerontology offers an overarching guide to supporting autonomy and promoting dignity for all older adults, it also includes the need to consider the individual in their entirety. These considerations include where a person lives and what physical or cognitive challenges they might face. However, these factors do not preclude moving away or toward safety or autonomy entirely based on a person's cognitive or living status.

Finally, the imperative of finding the balance between safety and autonomy brings us to the macro level of policy. Expedited federal, state, and local policy development efforts on behalf of older adults have been extensive. Although all social groups experienced the detrimental effects of COVID-19, older adults were disproportionately impacted. While these policy efforts have impacted older adults on a societal and community level, they have left gaps at the individual level. Thus, drawing from humanistic gerontological perspectives (Cole et al., 1992), political economy frameworks (Minkler & Estes, 1991), and critical gerontology (Phillipson & Walker, 1986) helps us identify forms of domination and explore possibilities of emancipatory social change. Stemming from our experiences during the pandemic, we are at a critical juncture in connecting person-centered theory and policy to rebalance aging services post-pandemic.

The Necessary Commute between Theory and Practice of Humanistic Person-Centered Gerontology

The impact of the COVID-19 pandemic calls for the practice of humanism to support both autonomy and safety. Governmental and health officials ask the general population to think of others by wearing masks, washing hands, and keeping considerable distance. However, older people have been asked to do much more. They were asked to stay in their homes and even stay in their rooms in congregate living communities. As a result, older people experienced the loss of autonomy and dignity in order to reduce risk and avert an overloaded healthcare system (Heid et al., 2021). Several questions will guide our exploration of theories to practice. First, what was the practice before the pandemic? Second, what occurred at the start of the pandemic? Third, what has been learned during the pandemic? Finally, what are the implications for the future?

What was Practiced Before the Pandemic?

Robert N. Butler (Butler, 1975) wrote his groundbreaking work, *Why Survive? Being Old in America* in 1975. Since that time, gerontology has endeavored to address how to reframe aging with effective practices to defeat ageism (Gerontological Society of America, 2020). For nearly 50 years, gerontologists have worked to inform an ill-prepared society of an unprecedented growth in the older adult population at home and abroad. The negative stereotypes of aging started to fade with the active engagement of older people entering later life striving to find more ways to live meaningful lives—travel, life-long learning, second and third careers, volunteerism of all kinds. Atul Gawande's *Being Mortal* (Gawande, 2014) began changing the societal view of what matters in later life—the freedom to live independent lives with dignity through individual choices. The GSA initiative, *Reframing Aging*, began pushing ageism away systematically through its communication strategies and educational efforts. Gerontologists have demonstrated that older people are individuals—unique human beings first—a heterogeneous population in which age is one of many descriptors and not the defining one.

What Occurred at the Start of the Pandemic?

At the beginning of the COVID-19 pandemic in March 2020, it seemed that hard work for the past half-century, which developed and promoted practices to support culture change and fight discrimination for older people was flipped back by a societal Maslowian response based on needs for safety (Maslow, 1943). The often-quoted qualifier “an abundance of caution” became a rationale for implementing restrictive practices limiting the personal freedoms of older people, especially in congregate care. This strict confinement of older people in senior living communities has had mixed results regarding efforts to deter the COVID-19 virus, contributing to

significant degeneration in the health and well-being of older adults and their care partners (Losada-Baltar et al., 2020).

What is Being Learned During the Pandemic?

Onsite services have pivoted broadly and rapidly to ameliorate unprecedented social isolation and loneliness (Kim & Jung, 2021; Spooner et al., 2019). These human-centered practices through humanities and the arts led to innovative programming mitigating isolation (Lem, 2020). Creative arts professionals joined forces with telemedicine, among other online services, to support older individuals and their care partners. For example, in a clinical setting, the [Georgetown Lombardi Arts and Humanities Program \(2020\)](#), artists in residence, who are usually at the patient bedside or providing programs for care partners, transitioned into making videos of performances and online classes in all the artforms, relieving patient anxiety and caregiver stress. In a congregate setting, [Arts for the Aging, \(2020\)](#), an organization that delivers multidisciplinary arts programs to adult day centers and assisted living facilities, redesigned its programming to yield live online workshops and new pre-recorded programming to engage older participants and their care partners. Finally, in a community setting, in Takoma Park, Maryland, Dance Exchange, which once led dance classes in person for older residences in public housing, now conducts them virtually as part of the City's Cultural Plan ([Dance Exchange, 2020](#)).

What are the Implications for the Future— Post-Pandemic?

The path from theories of humanistic gerontology and critical gerontology to effective person-centered practices has been accelerated and arguably augmented by the pandemic. Practicing person-centeredness has been essential during the pandemic to sustain the social fabric for older individuals, care partners, and the community at large to provide safety and promote autonomy and dignity (Corvo & De Caro, 2020). The resulting transformative innovations enhance the health and well-being of older adults. In the following sections, we explore humanism in person-centered care practices to balance autonomy and safety in various settings and care situations. We additionally focus on the importance of person-centered policy development to enable effective practices.

Autonomy and Safety Enhanced Through Social Connectivity Innovations in Senior Living Settings

The effects of COVID-19 on residents of long-term care and independent senior living communities have been conspicuous. Such communities, which include housing and care in congregate settings for adults in the highest at-risk age group for succumbing to the virus, have had to adjust on the fly to a pandemic never experienced by providers within the industry.

Of course, safety comes first from an organizational standpoint, but social connectivity remains a principal reason for such communities' very existence, particularly for those providing independent living, assisted living, or memory care services in congregate housing environments. Further, social well-being is recognized as an essential aspect of quality of life and care in long-term care communities, mainly via targeted federal regulations ([Improving Medicare Post-Acute Care Transformation Act of 2014, 2014](#); [Medicare and Medicaid Programs, 2016](#)).

Although the implications of the COVID-19 virus on safety have been heavily reported, less discussed has been the threat on daily life for all residents, in particular, safety regulations (aka "mandated social isolation") as required by the CDC, Centers for Medicare & Medicaid Services (CMS), and state and county Departments of Health (e.g., [Centers for Medicare and Medicaid Services, 2020a](#); [New York State, 2020](#)). These mandates have been applied with little or no input from residents or providers. For example, in most states, restrictions were applied to in-person visitor access for family and friends and limits were mandated on residents' freedom to leave a community unless medically required. Within the community, opportunities to engage via group dining, social activities, or even gathering in lounges or libraries were eliminated. Unfortunately, although potentially appropriate from a risk management perspective, these restrictions were contraindicated for emotional well-being and interpersonal relationships, both foundational to the senior living experience.

As a demonstration of balancing autonomy and safety, long-term care, and senior living communities, including skilled nursing facilities, assisted living, memory care, independent living, and full continuum continuing care retirement (life plan) communities, have turned to new and creative approaches to social connectivity (Saunders et al., 2020). See [Table 1](#) for examples of social connectivity programming.

Central to the development of these innovative approaches were humanistic, person-centered values that considered the need to promote autonomy and dignity and recognize older adults' requirements, including their need for social connection. We identified trending innovations across senior living settings based on the literature ([Whitehead & Torossian, 2021](#)) and our collective observations during the Georgetown University Aging & Health webinar. Each example of social connectivity programming in [Table 1](#) illustrates opportunities to address the social and physical distancing required yet also creates new and, in some cases, permanent models for expanding external and internal social connectivity moving forward.

Balancing Autonomy and Safety for a Specific Population: Persons Living with Dementia

COVID-19 further illuminated the need to balance autonomy and safety through person-centered practices for people living with dementia particularly because their autonomy is often seen as detrimentally limited through cognitive challenges.

Table 1. Social Connectivity Programming

Onsite Programming	
Connections using cars	Enables family and friends to celebrate holidays, birthdays, or special occasions by driving around the community in decorated cars, waving, and honking horns, as residents view from their balconies or windows
Group activities via public announcement (PA)	Uses the community sound system to conduct BINGO, trivia, exercise, singing, current events, or other scheduled group activities in real time
Programs through in-house TV channels	Streams activities such as pre-recorded or live exercise groups, movies, announcements, or specially created holiday video greetings from family and friends
“Window-to-the-World”	Provides a space for family and friends to visit outside the window of a resident’s room or in a designated, disinfected window viewing area, while communicating by phone
Family Circles	Establishes a designated indoor or outdoor area in which scheduled, socially distanced, and masked or partitioned in-person visits can be completed between residents and a limited number of family members or friends
Online and Technology-Based Programming	
Technology-assisted in-person communications	Allows residents to individually or with staff assistance to see and speak with family members and friends via tablet, smartphone, or camera equipped computers via FaceTime, Zoom, or other applications
Technology-assisted group applications	Allows residents to use internet apps to participate in online bridge groups or related games, or non-contact group activities such as Nintendo Wii bowling, golf, tennis, or trivia games
Virtual reality	Enables residents to “travel” to destinations and points of interest around the world or engage in simulated outdoor activity

Safety might be weighted more heavily than autonomy for people with dementia (Robinson et al., 2007). Therefore, this population may be at higher risk of being denied autonomy by care partners and others for the sake of safety.

Autonomy and risk in the lives of people with dementia have traditionally been framed as honoring individuals’ choices, desires, and decisions while balancing the impact on their (and others’) personal safety and well-being (Smebye et al., 2015). Nevertheless, there have been high levels of unease navigating this balance, particularly in settings such as long-term care, which have a robust risk management culture (Evans et al., 2018). In addition, the culture of dementia care itself reflects an imbalance, focusing more on reducing or eliminating risk than promoting autonomy (Kitwood, 1997). However, the diagnosis of dementia itself is not a barrier to autonomy (Dickins et al., 2018).

With COVID-19, these tensions of autonomy and risk have been further illuminated, mainly related to challenges reported by care partners as they implement infection control protocols. In their need to ensure the safety of persons with dementia and those around them, care partners saw the looming risks and were unsure how to support autonomy (Iaboni et al., 2020). These new tensions also raised questions about possible higher expectations for avoiding risk for people with dementia. Inherent in this conversation for gerontologists is the concern that people with dementia cannot accurately assess risk, resulting in an assumption that the need to emphasize risk avoidance is even higher. Although the cognitive challenges of dementia might validate this concern, it is also essential to consider that even for people who do not have dementia, their ability to evaluate risk

might not relate to their willingness to take it, and they might still place more emphasis on autonomy (Bonem et al., 2015). It is possible that a stronger emphasis on safety, resulting in higher limitations to physical or social environments, resulted in higher health risks to people with dementia (Olson & Albensi, 2021).

We suggest that our focus needs to be more on how we can honor and enable autonomy in people with dementia and, in doing this, minimize risk. Autonomy is often operationalized as the need to “allow” people with dementia to do whatever they want. However, this does not fully unpack the multi-dimensionality of autonomy. Autonomy fundamentally includes the need to see things from the perspective of the person with dementia, understand their motivations and needs, and best honor what is important to them (Weinstein & DeHaan, 2014).

For example, for a person with dementia who does not want to wear a face mask, a person-centered approach entails the care partner to consider who he or she is and what is important. A care partner might ask why an individual does not want to wear a mask, considering all the reasons behind that desire. These reasons might include the discomfort of the mask, a lack of clear and constant communication about the purpose of the mask, etc. Knowing the individual, a care partner might understand that this particular person is highly social and that wearing a face mask impedes the ability to smile and talk with others. As a result, a care partner might determine ways to ensure that she or he may continue to socialize, albeit in modified ways due to COVID-19. The care partner might also evaluate the situations in which it is more or less critical to wear a mask. It is important to note these

responses are driven by the needs of the person with dementia and the value of autonomy, rather than purely by risk avoidance. Yet, by focusing on the person's needs and by honoring autonomy, risk is still considered.

Through the lens of autonomy and risk, a person-centered framework includes recognizing that the emotional well-being of a person with dementia is equally as important as their physical well-being (Power, 2014). This framework provides ways to support people with dementia during COVID-19, or times of crisis, and beyond. To meet the needs of both the person with dementia and their care partner, we must adjust the way we see things and change our behavior rather than expecting a person with dementia to adjust or adhere to our expectations (Kitwood, 1997). This pandemic's unique experience has taught us that we should consider how a diagnosis of dementia impacts the way we operationalize person-centered values in balancing autonomy and risk and, perhaps provides additional insight into the need for "leading" with autonomy while considering safety for all older adults.

Addressing Safety and Autonomy with Person-Centered Public Health Policy

Over the last 20 years, it has been contended that age-related policies should include principles of person-centered care and be guided by metrics that assess how giving the individual what they want impacts cost, quality, and many humanistic outcomes (Epstein et al., 2010). Now in the face of a worldwide public health emergency, regulatory efforts developed at an expedited pace have been established and operationalized to strengthen public health. We argue that in the face of this significant public health crisis, overarching guidance procured to support overall public health has affected the quality of life of older adults, primarily individuals in long-term care settings. For example, regulatory efforts by the Federal government to isolate individuals in nursing facilities may have deleterious effects on residents, including depression and anxiety (Simard & Volicer, 2020). Any public health initiative must balance the need for protecting older adults while maintaining their need for autonomy and self-determination, primarily to support individuals who may experience inequalities in health (Kusmaul et al., 2020). To bolster dignity, respect, and independence for older adults in all living situations, integrating a person-centered approach in developing any aging policy is warranted.

In the time of COVID-19, policies that seek to promote general well-being, such as the [Coronavirus Aid, Relief, and Economic Security Act, \(2020\)](#), allowed for provisions to bolster services and supports, building capacity to safeguard older adults. For example, partnerships between physicians and older patients, forged out of compassion and need, may very well increase the autonomy and care of the nation's most vulnerable (Begun & Jiang, 2020; Simpson & Porter, 2020).

The COVID-19 pandemic has reignited the need to increase the timeliness and sensitivity of patient-level data and to advance an interoperable information-sharing structure to improve the patient experience (Boissy, 2020; Centers for Medicare and Medicaid Services, 2020b). Clearly, there is momentum to ensure person-centered care is instrumental in all health care activities in all care settings.

Federal policies such as the CMS's Requirements for Long-Term Care Facilities (42 CFR Subpart B) and the Improving Medicare Post-Acute Care Transformation Act of 2014 have pushed to improve all individuals' shared decision-making and autonomy in long-term and post-acute care settings. These policies have attempted to reinforce the resident's locus of control and to allow individuals to make their own choices to the greatest extent (Improving Medicare Post-Acute Care Transformation Act of 2014, 2014; Medicare and Medicaid Programs, 2016). Thus, maybe the increased focus on person-centeredness has not been stifled but reignited by this unimaginable public health crisis.

Although Federal agencies collect and report such COVID-related data, the need for increased research and data collection efforts emerge. Specifically, individual-level data will likely aid in care planning and delivery, reinforcing autonomy as a factor through individual decision-making. Moreover, a focus on improved standards of care, evolving care models, and the person's voice in all quality metrics becomes necessary to ensure person-centeredness is integrated into all facets of this work. Now more than ever, it is time to include the person in every part and at the core of every care setting.

Conclusion and Call to Action—Adoption of Humanistic Person-Centered Model to Support Research, Policy, and Practices

The national response to the COVID-19 pandemic has forced gerontologists to think, redesign, and innovate about humanistic person-centered policies and practices that support the health and well-being of older adults during everyday life and times of crisis. This culture change, of sorts, forces all gerontologists to question what it takes to balance safety and autonomy under the guise of health and well-being. What has been solidified from this public health emergency is that before the pandemic, there was already a pervasive risk-avoidance culture in person-centered care delivery (Behrens et al., 2020). The resulting innovations from the pandemic's need for restrictions on an individual's daily life, thus this problem of safety versus autonomy, do not have to be an either-or question. Instead, a person-centered continuum of care, based on humanism, establishes common ground between an older person's needs and preferences and their communities' ability to provide an autonomous and safe environment.

Further, person-centeredness has applicability for all older adults, even though traditionally applied to those living in independent senior living or long-term care communities, people with dementia, and the medical community. Hence, this call for action focuses on employing person-centeredness (person-centered values and principles) as a lens through which to develop and bolster policy and practice. This call for action includes but is not limited to the need for professional development of the aging services workforce to ignite further innovations that will eliminate the need for restrictions on older individual's daily life that detrimentally affects their dignity and overall autonomy. The COVID-19 public health emergency has forced us to rethink how we honor the individual humanness of each person while providing safety. Using humanistic person-centered values can actualize creative policies that consider the complexity and heterogeneity of older adults in the time of the COVID-19 pandemic and beyond.

In conclusion, to highlight the voices of older adults, we offer an example of person-centeredness in practice. "Project: Look Up" is a moving-art installation created with residents of Mt. San Antonio Gardens, a retirement community in Pomona, California. Artist Elizabeth Turk imagined illuminated umbrellas spreading hope during the pandemic. In making this sculpture, the voices of 500 residents and staff responded "yes" in answer to the question, "What do you tell yourself when you face adversity?" The artist recalled, "What better community to engage with to remind us of joy and resilience—vulnerable people leading us back to joy and togetherness" (Fung, 2020). These efforts advance the theories of critical gerontology through the practice of person-centered humanism, removing forms of domination and identifying possibilities of emancipatory social changes (Cole et al., 1992, 2010; Minkler & Estes, 1991; Phillipson & Walker, 1986).

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