

Special Issue: Gerontology in a Time of Pandemic, Part II: Forum

#MoreThanAVisitor: Families as “Essential” Care Partners During COVID-19

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Abstract

The public health response to the current Coronavirus pandemic in long-term care communities, including assisted living, encompasses prohibiting visitors. This ban, which includes family members, has been criticized for being unfair, unhealthy, and unsafe. Against this backdrop, I examine the roles family play in residents' daily lives and care routines. I argue that classifying family as “visitors” rather than essential care partners overlooks their critical contributions and stems from taken-for-granted assumption about gender, families, and care work, and I demonstrate why families are more than visitors. Policies that ban family visits also reflect a narrow understanding of health that focuses on mitigating infection risk, but neglects overall health and well-being. This policy further stems from a limited comprehension of care relations. Research shows that banning family visits has negative consequences for residents, but also families themselves, and direct care workers. I argue that identifying ways to better understand and support family involvement is essential and demonstrate the utility of the Convoys of Care model for guiding the reconceptualization of family in long-term care research, policy, and practice during and beyond the pandemic.

Keywords: Long-term care, Public policy, Quality of care, Quality of life, Assisted living

In the United States and across the globe, the public health response to Coronavirus Disease 2019 (COVID-19) in hospitals and long-term care settings, including nursing homes and assisted living communities, involves prohibiting visitors and nonessential personnel. Limiting access is a necessary and critical step toward curbing the spread of COVID-19 and protecting the lives of patients and long-term care residents, their visitors, the health and long-term care workforce, and the general public. At present, however, in most regions, family members are considered “visitors.” In response, scholars, health care professionals, and advocates are protesting the policy and practice of excluding family as being unequitable, unhealthy, and unethical (Stall et al., 2020). These protests appear in a myriad of outlets such as letters to editors, opinion pieces, and social media posts,

including many tagged with #MoreThanAVisitor. Such objections are justified.

Research on residents' family and friends in long-term care settings, for example, characterizes them as a “bed-rock” of the system, consistently demonstrating their status as essential care partners (Wolf & Jenkins, 2008, p. 198). Public health policies and practices responding to COVID-19 in care settings indicate a failure to recognize the significant nature of family involvement and the consequences of their exclusion. Such oversight demands consideration and deconstruction. In this forum article, I draw on existing theory and research to demonstrate that failing to recognize family contributions: (a) originates from taken-for-granted assumptions about gender, families, and care work; (b) stands in contrast to evidence documenting

family involvement; and (c) has dire consequences for all stakeholders. I focus on assisted living, but many observations apply across residential care settings, including the call for a new way forward for research, policy, and practice pertaining to families and long-term care.

Before turning to the origins of the “just visitors” issue, it is important to specify that, rather than being static, “family,” as scholars have long theorized, is a social process; it is something people “do” or “construct” in their daily lives, which leads to variability in what and who constitutes family (Holsten & Gubrium, 1999). Narrow definitions of family frequently do not reflect the way lives are lived or account for those who are marginalized based on social location (e.g., Stack, 1974). And, as assisted living research shows, “family” needs to be broadly defined as those related to residents by blood and marriage, as well as nonkin involved in residents’ lives, such as friends, neighbors, and church, sorority, and fraternity members (Kemp et al., 2018). Thus, hereafter, references to “family” encompass this broader, more inclusive definition, as it must also do in research, policy, and practice.

The Origins of Family as “Just Visitors”

The Invisibility of Care Work and Systems

Classifying family members as “visitors” in care settings stems from the taken-for-granted invisible nature of their contributions and a failure to view care networks and systems holistically. Seminal work informed by a socialist feminist perspective theorizes that the ideology of familism casts care as a family responsibility, characterizes family care as natural and preferred, and defines care as women’s work (Aronson & Neysmith, 1997). The gendered nature of care work, both paid and unpaid, means that its invisibility and devaluation are no coincidence (Parks, 2003). Moreover, long-term care settings are highly feminized as care work frequently is performed by and for women, which further compounds marginalization (Armstrong, 2018; Armstrong et al., 2012). Similar to other long-term care settings, assisted living is one in which the workers paid to provide the majority of hands-on care have among the lowest wages and status in the labor market (Kelly et al., 2020). As a largely for-profit industry, assisted living depends on uncompensated family labor—an industry feature that largely is overlooked and unquestioned in policy and in research. This arrangement further signals the taken-for-granted and gendered nature of care and the influence of structural factors, namely patriarchy and capitalism (see Ward-Griffin & Marshall, 2003).

Care work performed by family frequently is labeled “informal.” Levine and colleagues (2010, p. 119) argue, “The very language policy makers use is revealing. Family caregivers are called ‘informal’ caregivers to distinguish them from paid caregivers like nurses and aides. The term informal suggests casual, unstructured, unofficial care—pleasant, but not essential.” Many scholars use the label

“informal” because not everyone is technically family and some family members receive pay for their care (Kemp et al., 2013). More accurate concepts and better language in policy, practice, and research are needed. In their absence, I use the terminology, but with the caveat that the formal/informal categorization is a false dichotomy that gives the illusion that the two care sources are separate, exacerbates the invisibility of the unpaid family care, and is not reflected in actual care arrangements (Ungerson, 1990).

As Ward-Griffin and Marshall (2003, p. 193) note, applying a social feminist lens to the formal/informal dichotomy shows that “care work occurs in both the private and public spheres, and these spheres are interwoven, and that caregivers’ everyday experiences are inextricably linked to the larger political, social, and economic environments.” Thus, examining care arrangements reveals much about societies. Armstrong (2018), for example, argues that long-term residential care can be seen as:

... a barometer of values and practices; a signal of economic, cultural and social perspectives, raising issues that go beyond specific services and practices; issues such as human and social rights, the role of the state, responsibilities of individuals, families and government, work organization and skills; and notions of care. For all these reasons, long-term residential care deserves not only study but reimagining. (pp. 74–75)

Studying and reimagining needs to include understanding and recognizing family contributions, the roles families play in care networks, and the outcomes of banning visits for residents, care partners and networks, and the long-term care system. Doing so requires holistic care models.

Lessons From Holistic Care Models

Kemp and colleagues’ (2013) Convoys of Care model takes a holistic and integrative approach to theorizing intersections of formal and informal care. It assumes that most individuals in need of care are situated in care convoys (i.e., networks) comprised of the care recipient and a dynamic constellation of care partners. Derived from a synthesis of theoretical and empirical work, this model builds on Kahn and Antonucci’s (1980) convoy model of social relationships, which views individuals as surrounded by an evolving social network comprised of close personal relationships and offers a theoretical lens through which to understand the connection between social relationships, health, and well-being.

The Convoys of Care model (Kemp et al., 2013) expands the convoy to encompass those who provide paid care, offering a conceptual and methodological framework for studying the intersection of formal and informal care. The model posits that care networks and negotiations are shaped by factors at the levels of individuals, dyads, care networks, care settings, and industries, as well as

community and societal levels. State policies that frame families as nonessential visitors attest to the influence of macro-level factors, raising important questions about care values, structures, and priorities.

Attending to care convoys in research, policy, and practice is infrequent, yet necessary for and consistent with holistic models of person-centered (Kitwood, 1997) and relationship-centered care (Nolan et al., 2002), which view care as an inherently social process, place value on self and identity, and emphasize the relational dimensions of care, including the interconnectedness and interdependencies associated with care, and the need for collaborative care partnerships. Building on these approaches, Kontos and colleagues (2017) advocate for a “relational citizenship” approach, which draws attention to freedom, human agency, interconnectedness in care relationships, and power relations in individuals’ lives. Collectively, these models stand opposed to the medicalization of dementia, which equates persons with their diagnosis and places emphasis on controlling and managing illness through clinical intervention. Although derived from research focused on people with dementia and their care partners, given the vulnerabilities of those who live and provide care in residential long-term care settings (Armstrong et al., 2012), analytic attention should be paid to these phenomena universally.

Parks’ (2003) feminist critique of the home health care industry speaks to the concept of “relational autonomy,” whereby she addresses issues of interconnectedness among care providers and recipients, also noting that issues of self and identity are bound up in care relationships and shaped by political and economic contexts. As Kemp and colleagues (2013) argue, assisted living residents and family members have power as consumers. Yet, they also are dependent on staff for care, which makes them vulnerable, especially residents. Staff have power as hands-on care providers, but are vulnerable given the low status they occupy in the social structure. Meanwhile, Perkins et al.’s (2012) model of relational autonomy in assisted living emphasizes links between residents’ sense of autonomy, including the relationships and settings in which they are embedded.

Armstrong (2018) highlights tensions in residential long-term care settings that affect residents’ care experiences and are relevant to deconstructing family visit bans. First, is the tension between medical and social care. The former refers to clinical intervention, whereas social care encompasses activities of daily living, recreation, talking, and social support (see also Twigg, 2000). Armstrong posits that the ways medical and social care are balanced influence and are influenced by regulatory factors, care practices, environmental design, and funding models. Next, and related, Armstrong (2018) points out that most residential long-term care communities purport to offer home or home-like environments. Yet, the physical environment and regulation of daily life frequently appear institutional/clinical in nature.

Policies prohibiting family visits are guided by a biomedical model that prioritize infection control. It disregards the

social and relational aspects of care, neglecting the mental health and well-being of older adults and those who care for them. The COVID-19 pandemic renders these aspects of care visible and increases the need for care models that foreground selfhood, human connections, and partnerships between care recipients and their paid and unpaid care partners in the provision of quality care. The absence of families in long-term care settings compromises care partnerships; families do more than visit.

Families in Assisted Living: #MoreThanA Visitor

Nursing homes receive more attention than assisted living when it comes to COVID-19, including critiques of restrictive visiting policies. Yet, as Zimmerman and colleagues (2020) note, assisted living residents resemble nursing home populations with high rates of chronic disease and multiple comorbidities, including conditions that heighten COVID-19 risk (see also Kistler et al., 2016). Dementia rates also are high and most residents are advanced in age (Caffrey et al., 2012; Zimmerman et al., 2020). Unlike the nursing home industry, however, in the United States, assisted living is not federally regulated. Family contributions are important in both settings (Grabowski & Mitchell, 2009), possibly more so in assisted living (Jackson & Gaugler, 2016).

Although variable nationwide, assisted living is largely a nonmedical residential care setting based on a social, rather than a medical, care model (Carder et al., 2015), with the tension between the two models escalating. In order to meet residents’ health care needs, providers frequently rely on external health care providers, including hospice and home health (Harris-Kojetin et al., 2019). Assisted living staff, especially direct care workers, provide most hands-on care with family members contributing in a variety of ways to residents’ care convoys (Kemp et al., 2013).

National data show that most, though not all, assisted living residents have at least one family member with whom they communicate regularly by phone or through in-person visits (Sengupta et al., 2019). Perkins and colleagues’ (2013) study of assisted living residents’ social networks found that 99% of resident participants ($n = 192$) included family in their networks. Family members represented 66% of all network members and also comprised the majority of people in residents’ inner circles, indicating that they could not conceive of living without them. Having a higher proportion of family in one’s social network also was the strongest individual predictor of resident well-being. Recent research shows that family members regularly engage in emotional, intellectual, spiritual, and physical intimacy with residents; family also help residents cultivate connections with others (Fitzroy, 2020). Family members engage residents in activities, facilitate social participation, and provide meaningful and important connections beyond the care community (Ball et al., 2005).

Family visits contribute to residents' social and emotional well-being, which is justification enough, but visits rarely are exclusively social in nature (Jackson & Gaugler, 2016). For example, staff rely on family to bring certain supplies, including medications, body wash, and incontinence pads or residents favorite snacks, all of which affect workers' ability to execute care properly and cater to residents' preferences (Kemp et al., 2009, 2010, 2019). Family members typically advocate to ensure that residents' care needs and preferences are addressed (Kemp et al., 2013). Part of visiting involves "checking-in." Consequently, family sometimes describe themselves as "an interested party" or "a squeaky wheel" (Kemp, 2012). Family advocacy includes providing information that helps staff know residents and, ultimately, deliver more personalized care than would otherwise be possible; some staff say such knowledge makes them want to do more for residents (Kemp et al., 2010). Family members also are essential for monitoring residents' health and in identifying significant health status changes, some prior to being noted by staff, helping to prevent health crises (Kemp et al., 2020). Resident health care needs in assisted living are considerable, highly individualized, and involve a "mosaic of care arrangements"; family members are key players in care coordination and facilitating access to medical professionals and health care appointments (Kemp et al., 2019).

Finally, although less frequent, families provide hands-on care to residents (Jackson & Gaugler, 2016). This care sometimes involves residents with dementia or those with limited physical function (Kemp et al., 2018). In certain cases, families provide this care because staff are unable or because they want to help with tasks like bathing and grooming, help that is welcomed by staff (Bauer et al., 2014).

Care Relationships Stakeholder Consequences

Understanding the consequences of banning family visits requires a consideration of entire care networks, including their structure and function. Assisted living research shows that the most effective care convoys, those that best support residents' ability to age in place with optimal quality of life and care, involve families and are characterized by effective communication, collaboration, and consensus among residents and all care partners (Kemp et al., 2018). Most convoys change over time, including ebbs and flows related to family involvement (Kemp et al., 2017). Yet residents with involved family generally fare better in terms of receiving timely and appropriate care and ability to age in place relative to those without such support (Kemp et al., 2018). Some residents have no family on which to rely or have families who are unable or unwilling to be involved, and, in select situations, residents need protection from family (Kemp et al., 2020). Staff complain when they feel that families provide inadequate support (Kemp et al.,

2009), sometimes growing closer to those without positive family involvement and stepping in to fill voids (Kemp et al., 2010). Given their pivotal roles, the presence or absence of families in long-term care settings has reverberating effects with outcomes for all stakeholders.

Care work involves what Twigg (2000) refers to as "bodywork" that entails working on and manipulating others' bodies and, in many cases, intimacy, which demands significant emotional labor requiring workers to manage their feelings in normative ways and involves the commodification of emotions (Hochschild, 1973). Prior to the pandemic, direct care workers frequently reported feeling pressed for time to complete care tasks, with some reporting feeling frustrated by not having sufficient time to talk with or provide social support to residents (Ball et al., 2010). During the pandemic, these already vulnerable workers must not only carry on doing their jobs but manage COVID-related risks, fears, and realities, including death and illness, and also fill voids.

The absence of families leaves significant care delivery gaps. Social support and the provision of supplies can be contributed remotely, but doing so requires resources and staff facilitation, adding to workloads. Although family members can check in with and advocate for residents remotely, being on-site typically allows family members to assess care directly rather than relying on residents or staff. For residents unable to communicate, families must depend entirely on providers for information, placing additional burden on staff. Virtual health care delivery during the pandemic also requires staff facilitation. Meanwhile, hands-on care from families cannot be performed remotely, creating additional staff burden or unmet resident needs.

Lack of in-person family involvement significantly compromises resident care, jeopardizing their health and well-being. Across the globe and in various care settings, reports exist of ensuing escalation in isolation, loneliness, anxiety, and depression and accelerated cognitive and physical decline, especially among long-term care residents with dementia (Simard & Volicer, 2020; Suarez-Gonzalez, 2020). Concerns that restrictive policies are doing more harm than good also point to suffering among families and care staff (Stall et al., 2020).

The evidence presented above shows that without family support, care staff attempt to fill the voids, which during COVID-19 may require them to be all things to all residents, placing greater burden on staff. Amidst the uncertainty, fear, and risk created by the pandemic, the pressure on care workers to do more likely will take physical and mental tolls. Relative to the overall U.S. labor force, these workers are more apt to be female, nonwhite, and foreign born (Kelly et al., 2020) and, hence, occupy precarious social locations. Staff members' physical and mental health are at even greater risk without family visits, increasing work, health, safety, and social justice concerns and creating a significant public health issue for staff, with considerable repercussions for resident quality of care and life.

For their part, many families are experiencing anxiety, fear, guilt, and even depression as a result of being unable to participate in resident care in pre-pandemic ways (see [Ducharme, 2020](#)). These negative experiences are escalated further in settings directly affected by COVID-19 cases and in residents' end-of-life care and death. Family members' health and well-being also are at risk by their exclusion, further exacerbating the public health consequences of the pandemic.

Continued prioritization of the medical over the social and relational aspects of care escalates the vulnerability of residents, families, and care workers. Prior to the pandemic, [Armstrong and colleagues \(2012\)](#) argued that long-term residential care can be used as an indicator of equity in welfare states. They point out that long-term care residents are among the "most vulnerable and neglected populations" (p. 52) and their care is "intimately related to working conditions" (p. 55). Thus, they posit that the treatment of those who provide and receive care in these settings reflects the degree to which a state is dedicated to its citizenry and to promoting living with dignity and respect for all.

A New Way Forward

In the United States, under the Secretary of Homeland Security mandates, the Cybersecurity and Infrastructure Security Agency secures critical infrastructure and identifies those workers involved in health care and public health that are essential components. The research outlined above demonstrates that families contribute essential care and consequently represent an important piece of the critical health care infrastructure. Considering families "visitors" in policy goes beyond inaccurate portrayal of their roles and should be challenged. Research underscores the need to keep family informed and involved in residents' lives to the greatest extent possible ([Zimmerman et al., 2020](#)). In the absence of a vaccine, cure, or treatment and, in preparation for future public health emergencies, researchers, policy makers, and practitioners must conceptualize family members as #MoreThanAVisitor. Their contributions have significant implications for the health and well-being of residents and staff and suggest the need to move beyond a biomedical response to care more generally.

Family visits are possible. A Dutch national study involving 26 nursing homes reported that lifting visitor restrictions by allowing families to return under certain conditions (e.g., use of personal protective equipment, social distancing) was welcomed by all stakeholders, brought joy to residents, staff, and families, and had a positive influence on resident well-being ([Verbeek et al., 2020](#)). This example holds promise, but begins with recognizing the centrality of families as part of the residential long-term care system.

The Convoys of Care model ([Kemp et al., 2013](#)), with its holistic view of long-term care, provides guidance for reconceptualizing care relationships during the

pandemic and afterwards. The model demonstrates that the interconnectedness and interdependence among care recipients and care partners are consequential and must be considered by researchers, policy makers, and practitioners. It also draws attention to the multilevel contexts influencing care relationships.

The pandemic and related policies are dramatically influencing care processes. Reversing course to reintroduce family during the pandemic increases infection risk and thus requires identifying appropriate parameters. Research guided by the Convoys of Care model shows that most assisted living residents' care networks are led by a primary family member, and, in some instances, care responsibilities are shared ([Kemp et al., 2018](#)). This observation suggests that in most cases, a single family member can be identified as essential. Determining when and under what circumstances these essential care partners participate in resident care should be negotiated on an ongoing basis within convoys and individualized based on residents' needs and preferences and the resources and capacity of their convoys, all of which may change over time.

The Convoys of Care model offers a new way forward for conceptualizing, studying, and improving care processes and relationships. As the model demonstrates, care relationships and networks, including how they are structured and operate, have consequential implications for care recipients' quality of life and care, for direct care workers' work quality of life, and for family members' care experiences ([Kemp et al., 2013](#)). Moving forward, the dynamism and interdependence of care relationships, networks, and systems must be attended to and placed at the forefront of research, policy, and practice related to families and long-term care and to quality improvement. Identifying ways to include, recognize, and better support family involvement or compensate for its absence is critical not only for residents, families, and staff, but entire communities and society at large.

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Conflict of Interest

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