

Building a Society That Values Care

Covid-19 in an Aging Society

By Kathryn Cai

With the population aging in the US as in many Western countries, COVID-19 has only revealed an increasingly urgent need for care. But the lack of support for caregiving is an ongoing and increasingly shared struggle. How can we care for the caregivers, and build a society that values care?

In order to offer varied perspectives on the pandemic, *Public Books* and *Books & Ideas* team up to offer a collaborative series on Covid-19. This article is published as part of this partnership.

At the hospice where her aging mother was receiving care, Liz O'Donnell had a revelation. A marketing executive at the time, O'Donnell had an exchange with another woman—a hospice nurse named Peg—that changed the way she thought about care. "Listen, I get it," Peg said to O'Donnell. "You're the sole breadwinner. I'm a single mother of two teenage girls. I get it." That scene appears in *Working Daughter:*

A Guide to Caring for Your Aging Parents While Making a Living,¹ the book O'Donnell wrote to explain the unique challenges of caregiving today, particularly for women.

Although Peg disappears into the background of O'Donnell's own caregiving story, Peg's brief but transformational interjection speaks to the countless other care workers who support families—and the lack of protections these carers experience. A single mother working as a hospice nurse, Peg very likely has limited resources to take care of her own family, even as she cares for other families. And so, the reality of limited resources faced by family caregivers like O'Donnell also extends to the caregivers who support these families. This scarcity of resources determines who can even be recognized and included in the already marginalized narrative of caretaking. Only by expanding that narrative—and fully recognizing the crucial labor that care workers perform—can we hope to support all of those who give care and, thus, strengthen our collective wellbeing.

The COVID-19 pandemic reveals how the fragility of our healthcare system—as well as the utter lack of policy protections to account for adequate healthcare, family care, and sustainable livelihoods—endangers us all. Though acutely visible now, the lack of support for caregiving is an ongoing and increasingly shared struggle, as demonstrated by the raft of new books that tackle the subject.

Self-Care Books for Caregivers

Some of these books fit squarely—if usefully—into the genre of self-help for family caregivers: O'Donnell's *Working Daughter*, for instance, or Donna Thomson and Zachary White's *The Unexpected Journey of Caring: The Transformation from Loved One to Caretaker*.² Others address the crucial role that paid caregivers are increasingly playing and the broader need for structural care in communities of color. These include Ai-jen Poo's *The Age of Dignity: Preparing for the Elder Boom in a Changing America*³ and Mikki

¹ Liz O'Donnell, *Working Daughter: A Guide to Caring for Your Aging Parents While Making a Living*, Rowman & Littlefield, 2019.

² Donna Thomson and Zachary White, foreword by Judy Woodruff, *The Unexpected Journey of Caring: The Transformation from Loved One to Caretaker*, Rowman & Littlefield, 2019.

³ Ai-jen Poo, *The Age of Dignity: Preparing for the Elder Boom in a Changing America*, New Press, 2015.

Kendall's *Hood Feminism: Notes from the Women that a Movement Forgot*.⁴ Taken together, these books reveal the burdens placed on individual caregivers when structural supports are lacking and suggest how we might build a world in which caregiving is valued and protected work.

In the midst of our current crisis, this work becomes both more important and more difficult than ever, as families are left to find ways to manage on their own and care workers are afforded little protection to safeguard their own health. These extreme circumstances can help us to recognize more clearly than ever how care work enables society as we know it to function. Our ability to go to work, for example, might rely on our capacity to entrust those we love to the care of others. Our collective capacity to weather crises depends on protecting the people who do this work, but our policies do not reflect this crucial interdependence. It is time to open our eyes to the care work that already surrounds and supports us every day, and to call for social policies that will fundamentally enlarge our individual and collective capacities to care for ourselves and our loved ones. These policies could include, for instance, universal family care. After all, this capacity to care—to afford childcare, to take time away from work when our loved ones are ill, and to provide an end of life filled with love—is one we all desire.

A Feminist Project

Feminists of color have long called for a radical expansion of care in our society. This can be seen in movements led by women of color that have demanded an end to the systemic harms their communities face. We can understand these demands as a call to care about their communities in material ways, supported by large-scale shifts in culture and policy. It is time for us to take up these calls to build caring structures. But we can do this only if we understand how the thriving of communities *that are not our own* is, nevertheless, integral to our own wellbeing. In the case of care work, this expansion would entail, firstly, recognizing the care work that the Pegs of the world do, and not just the work of the O'Donnells. Secondly, such an expansion would

⁴ Mikki Kendall, *Hood Feminism: Notes from the Women that a Movement Forgot*, Viking, 2020.

require material support for all caretakers—both the Pegs *and* the O'Donnells—in the form of fair wages, job protections, healthcare, and insurance coverage.

The call to value and protect care work is a feminist project. Family caregivers (like O'Donnell) are overwhelmingly women. Similarly, the overwhelming majority of people who provide paid care (like Peg) are also women: indeed, women make up around 85–90 percent of this sector, which includes home care, other forms of residential care, and nursing-home care. The majority of these carers are women of color, and one in four of them is an immigrant. The work that both family caregivers and paid carers do is intertwined. And this interdependence shapes the health and wellbeing of individuals and families across generations, as children, parents, and elders all feel the effects of either strained or ample resources. The feminist project of making caregiving more sustainable therefore benefits us all.

The dire condition of elder care during the COVID-19 pandemic perfectly illustrates this fundamental relationship between both sets of women caregivers. The crisis has exposed the vulnerability of our elders, alongside that of the relatives and professionals who take care of them. Elders have been exposed to COVID-19 in nursing homes and assisted living facilities, while those still living independently may not have caretakers to assist with procuring essential items or staving off loneliness. Family members who care for elderly relatives are left with little outside support. Meanwhile, nursing-home workers and home health aides are often paid meager wages and are themselves uninsured. While all of these people often come from very different racial and class backgrounds, the acute dangers of the pandemic show us their shared precarity.

In the case of care work, building care into our policies and institutions means adequate compensation and protections for paid care workers through initiatives like the *Domestic Workers Bill of Rights*. It also means policies like *universal family care*, which would fund family care at all stages of life, not just elder care. This crisis also makes clear that we must shift our priorities and enact caring policies in all facets of our everyday lives. This crisis can teach us, if we're willing to learn, that building equitable policies in health, housing, education, and environmental sustainability could create the resilience to collectively nourish us in the long term.

Caring for an Aging Population

With the US population aging, COVID-19 has only revealed an increasingly urgent need for support. The number of US residents aged 65 and older is only growing, and these elders express a clear preference for aging and dying at home.⁵ A 2019 study found that between 2003 and 2017, “natural deaths” that occurred at home came to surpass those in hospitals by a small percentage.⁶ This shift has also drawn attention to the demands that families must meet to provide care. While many families want to take care of their aging loved ones at home, they are faced with enormous emotional and practical challenges. Many family caregivers are not trained to provide constant physical and emotional support, and family caregivers commonly express their lack of preparation for the range and intensity of the tasks they must perform.⁷

A growing body of practical guides for family caregivers addresses everything from structuring a daily routine to advocacy techniques for promoting families’ interests. These titles, written in the style of self-help manuals, reflect the reality that most caretakers must find a way to adapt themselves to the enormous task of providing daily care for loved ones. In *Working Daughter*, O’Donnell shares her growing rage as her duties pile up while she fails to receive the necessary emotional support from her family and friends and accommodations from her workplace.

Eventually, however, O’Donnell begins to see “the upside”: the self-worth, closer relationships, and sense of meaning that can come with caregiving. This is called the “caregiver’s gain” in social science and physiological research. This upside is a particular encapsulation of the meaning that can emerge from caregiving relationships, which are important parts of the human experience. We should not instrumentalize this meaning, however, as personal consolations for the inadequacy of social policies to support caregivers. O’Donnell’s section entitled “Keep Choosing” is about continuously embracing the role of caregiver. The suggestion to “begin with the end in mind” — adapted from Steven Covey’s business self-help book *The 7 Habits*

⁵ Andrew W. Roberts, Stella U. Ogunwole, Laura Blakeslee, and Megan A. Rabe, “The Population 65 Years and Older in the United States: 2016,” United States Census Bureau (October 2018); Mark Mather, Linda A. Jacobsen, and Kelvin M. Pollard, “Population Bulletin: Aging in the United States,” Population Reference Bureau, vol. 70, no. 2 (2015).

⁶ Sarah H. Cross and Haider J. Warraich, “Changes in the Place of Death in the United States,” *New England Journal of Medicine*, vol. 381 (2019).

⁷ Ángela María Ortega-Galán et al., “The Experiences of Family Caregivers at the End of Life: Suffering, Compassion Satisfaction and Support of Health Care Professionals,” *Journal of Hospice and Palliative Nursing*, vol. 21, no. 5 (2019).

of *Highly Effective People*—prompts the reader to visualize the rewards of caretaking. “Speak your truth” gives the reader permission to “complain, wail, sob, or whine,” but then instructs them to “move on.” While the desire for such concrete steps is understandable, O’Donnell’s focus on the individual does nothing to change the larger structures that make caregiving an unsupported individualized burden in the first place.

The stress on personal transformation can also take a more relational and philosophical approach. Thomson and White’s *The Unexpected Journey of Caring* describes the ongoing act of caring for a loved one as a shared journey—a project of building a world together. For them, “looking into the eyes of a loved one and touching her hand is the beginning of resolve to harness love as the fuel for building a new kind of future together.” Thomson and White engage more deeply with the fundamental value of relationships that take shape through caregiving. But again, their focus on the private caregiving relationship assumes a family caregiver and does not address broader social structures.

While these volumes vary in tone, it is clear that the individualized focus comes by way of necessity, since family caregivers are provided neither social recognition nor material support. O’Donnell does mention the potential changes to tax and work policies that could support caregivers. But she notes that “until those things happen, caregivers must advocate for themselves and prepare for their roles.” The need for such individualized answers is understandable, given the current conditions of care work. But focusing solely on adjustments that individual family caregivers can make obscures the larger shifts that must take place in order for care work to receive the support and recognition that would benefit us all—both caregivers and those cared for.

Beyond Mainstream Claims

While labor activist Ai-jen Poo articulates the incredible strain on families who provide care, she does not blindly reinforce these families’ responsibility to meet and accommodate this strain. Instead, Poo concludes that “family members cannot possibly be relied upon to meet *all* the needs of the largest generation of older Americans ever.” She argues that “breaking the isolation that has come to define the

family caregiver experience, once and for all,” will require protecting and recognizing the other caregivers who are becoming increasingly involved in family care. Many families already rely on paid care, whether in the form of nursing homes or home health aides. The number of people in this profession increased from 2.9 to 4.5 million between 2008 and 2018. The sector is expected to grow by another 1.3 million people from 2018 to 2028, adding more jobs than any other sector in the US economy.⁸ While the work of care is extremely exacting, many of these workers are paid very little for their work: 15 percent of direct care workers in the US live in poverty and 44 percent live in low-income households.⁹

We must continue to ask ourselves whose rights and needs are recognized in calls for structural change. As activist and cultural critic Mikki Kendall argues, mainstream feminism continues to privilege the interests and voices of a small subset of women who are mostly white and well off. Kendall’s *Hood Feminism: Notes from the Women that a Movement Forgot* calls on the mainstream feminist movement to examine its own exclusions, which are often rooted in racist and classist biases about the kinds of issues that are important or worthy of attention. Kendall builds on the legacies of feminists of color to articulate how housing, hunger, and gun violence are important feminist issues that affect women in particular ways. These issues also shape the lives of the women whom we call on to care for family members. The lack of investment in their wellbeing impedes our capacity to build a more caring world in which everyone has the ability to lead healthy and sustainable lives.

Such a world requires wages that provide for more than just the bare minimum of daily sustenance, job protections, and the ability to live in safe neighborhoods free from the toxicity of violence and environmental pollutants. We must recognize that care is central to making our lives not just livable, but joyful and sustainable. Creating a sustainable approach to care will require that we center a commitment to mutual thriving—recognizing our shared stake in building more equitable and resilient social structures that enable care.

The current state of elder care illustrates the burdens that we are asked to take on individually when there are no structural provisions for care. The stories that are emerging from the COVID-19 pandemic should alert us to the urgent need to build a

⁸ Kezia Scales, “It’s Time to Care: A Detailed Profile of America’s Direct Care Workforce,” PHI (2020).

⁹ *Ibid.*

different world: one in which we see the myriad types of work that go into maintaining daily life as valuable and dignified labor, worthy of our respect and protection.

Further reading

- Liz O'Donnell, *Working Daughter: A Guide to Caring for Your Aging Parents While Making a Living*, Rowman & Littlefield, 2019
- Donna Thomson and Zachary White, foreword by Judy Woodruff, *The Unexpected Journey of Caring: The Transformation from Loved One to Caretaker*, Rowman & Littlefield, 2019
- Ai-jen Poo, *The Age of Dignity: Preparing for the Elder Boom in a Changing America*, New Press, 2015
- Mikki Kendall, *Hood Feminism: Notes from the Women that a Movement Forgot*, Viking, 2020

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