The Inevitability of Reimagining Long-Term Care

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Long-term care has been reimagined for as long as it’s been recognized, which in part explains the multitude of options that emerged during the mid-20th century growth of formal long-term care support in the United States and other developed nations. The articles in JAMDA’s special issue on Reimagining Long-Term Care propose ways to further reimage care going forward; this editorial calls the question as to whether we’ll ever stop reimagining long-term care, and posits that we won’t, for better and for worse. For better, because there’s always room for improvement and consumer desires will continue to evolve. For worse, because the absence of a “system” of long-term care virtually ensures different visions between factions and partial progress at best.

On that point, let’s correct 2 erroneous beliefs. Long-term care—services delivered over a sustained period of time to persons with cognitive or functional limitations—is not a “continuum” nor a “system.” As but a few examples, if it were a

continuum, we’d expect the prevalence of functional impairment to be less among persons receiving adult day services than among persons in assisted living, when in fact the percentage of persons with 3 or more limitations in activities of daily living is virtually identical (64% and 61%, respectively). Or, we’d expect the percentage of persons with arthritis, diabetes, heart disease, or hypertension to be lower among home health agency users than among assisted living or nursing home residents, which it isn’t. And if long-term care were a system—by definition, “a set of things working together as parts of a mechanism or an interconnected network”—we’d not have the situation in which hospital costs to Medicare and nursing home costs to Medicaid were on a different ledger, or that specific models of care would be needed to improve and reduce transitions across care settings. The lack of a system makes long-term care incredibly complex.

Areas in Which to Reimagine Long-Term Care

Attesting to the complexity inherent in long-term care, each article in JAMDA’s special issue highlights a different topic, yet every article points to the interrelatedness of all topics. This editorial groups the articles into 5 areas and notes interrelationships among them:

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workforce; societal issues; models of long-term care; financing, payment, and regulations; and long-term care services.

Workforce

Today, one of the topics most requiring reimagination is the long-term care workforce. We didn’t need COVID-19 to highlight historic issues related to burnout, understaffing, and the low regard bestowed on the long-term care workforce, but it certainly did that. In this issue of *JAMDA*, the article focusing on transforming direct care notes that the recent unprecedented federal and state attention on long-term care makes the time ripe for a national direct care workforce strategy, which could perhaps be incorporated into federal funding and accountability mechanisms. Beyond nursing assistants, there is need to revisit the availability of nurses, whose capacity could be augmented by employing foreign-educated nurses, albeit requiring an eye toward equity and necessary preceptorship. Going one step further, another article stresses that the future includes a more decisive role for nurse practitioners but notes that changes are needed to restrictive practice acts and that better differentiation is needed between their responsibilities and those of physicians. The role of physicians is also reimagined in an article on assisted living, proposing structured medical care led by a medical director, while also noting related controversies such as implications for continuity of care.

Reimagining the long-term care workforce would not be complete without addressing technology and families; the critical role of both came to the forefront during the pandemic. A pragmatic innovation presents experiences using a robotic device to enhance provider presence in nursing homes; it limited staff burden but has cost implications if it is to be routinely incorporated into care going forward. Regarding families, evidence recommends that residential long-term care embrace a more family-centric perspective, including involving families when developing organizational governance policies. There is also a need to maintain focus on respite for family who provide care at home, embracing new models borne out of COVID-19 such as supervision of care recipients by offsite respite providers via an interactive computer screen. Both articles envision a more empowered role for families, recognizing their critical role especially in light of staffing shortages.

Societal Issues

Three articles speak to societal issues inherent in long-term care that require attention. A special article addressing systemic racism presents 7 recommendations to address racial and ethnic disparities in long-term care based on existing evidence, addressing topics ranging from needs of family caregivers, to redesigning pay for performance programs, to culture change. In a different context, culture change is addressed in an editorial stressing the need to build trust in post-acute and long-term care, tasking medical care providers to help the field move away from a fear-based work culture. In yet a different context, a special article goes beyond the concept of a “safety culture” to a “just culture” and provides guidance for organizations to focus not only on outcomes but also on behavioral choices; in so doing, changes are needed both to the culture of the long-term care setting and to the survey process.

Models of Long-Term Care

There is much to reimagine based on international models of long-term care, as described in 7 articles in *JAMDA*’s special issue. Four articles provide broad recommendations or emerging models of long-term care. One is a World Health Organization global expert consensus report recommending 50 broad-reaching long-term care services. Another describes Costa Rica’s new national long-term care service program that is expected to inform the efforts of other middle-income countries. A third article describes a Dutch network to treat residents with any of 7 rare conditions for whom there is a need to improve care, collaboration, and competencies (eg, Huntington disease, Korsakoff syndrome, mental and physical multimorbidity), and a fourth article describes the Netherlands’ efforts to address the needs of persons with young-onset dementia. In addition, 3 evidence-based international articles speak to collaborative models that have promise for the future: a generalist-specialist collaboration with elderly care physicians embedded in primary care and 2 types of collaboration between long-term care settings and hospitals.

Three articles address the future of 2 consequential models of care in the United States—post-acute care and assisted living. An editorial questions whether a nursing home can and should provide both post-acute and long-term care, based on the challenges of providing optimal care to very different populations, disparities in care, and a shrinking market. A special article speaks to tensions that have affected the very fabric of assisted living, noting that today’s assisted living is not as intended and must be reimagined, suggesting numerous potential solutions to move toward that future. A third article describes a quality improvement collaborative that could serve as a model to guide assisted living moving forward.

Financing, Payment, and Regulation

Although explicit or implicit in virtually every article related to workforce, societal issues, models, and services, 2 articles in *JAMDA*’s special issue focus squarely on financing, payment, and regulation. The first addresses the current patchwork, variability, and insufficiency of funding, and the resulting barriers to care, quality, equity, and efficient allocation of resources; in reimagining, it envisions a new federal long-term care benefit and its essential features, as well as related tradeoffs and challenges. In a different vein, a nationwide study provides a new vision for regulations related to architectural design, calling for more single-occupancy rooms and more spacious living areas after finding associations between residential density and COVID-19 cases and deaths. COVID-19 will abate with time, but concern regarding infection transmission in long-term care will be never-ending.

Long-Term Care Services

Four articles speak about the type of services provided in residential long-term care. Consistent with the point above, a letter stresses the ongoing need to focus on infection control, and another calls to focus more closely on relocations within long-term care. Two special articles delve more deeply into care itself. One addresses recommendations for nutrition care and mealtimes, identifying which recommendations are most feasible and the related need for funding, policy, and practice standards. The second equates high-quality nursing home care with palliative care, also noting the critical role of payment policies and regulations.

Research to Reimagine Long-Term Care

All of the articles in *JAMDA*’s special issue on reimagining long-term care draw on literature and research to support their recommended vision for the future. That said, virtually every article also speaks to the need for additional research to guide implementation and examine outcomes, including but not limited to determining the impact of wage increases, training, and models of staff supervision; considering how best to implement a “just culture”; developing and implementing new models of assisted living and related regulatory requirements, financial incentives, and access; examining the costs associated with federal long-term care policy; and developing valid and reliable measures to evaluate the quality of and set benchmarks for palliative care.
Why It’s Inevitable That We’ll Forever Be Reimagining Long-Term Care

More than 30 years ago, Bob and Rosalie Kane wrote, “Given that our present long-term care is faulted on the grounds of both quality (public and private), little will be lost by trying a new approach.” (p628) That statement remains true today. The articles included in the special issue of JAMDA make clear that reimagining long-term care implicates complex interrelationships between the workforce, societal issues, models of long-term care, financing, payment, regulations, and services. On the one hand, those interrelationships make it challenging to effect change; on the other hand, change in one area can have a domino effect in improving outcomes as long as none of the dominoes impede progress.

Everyone wants long-term care to be reimagined toward a better future, but like so many other issues affecting the world, achieving that change is politicized. For the foreseeable future, it may be best to consider that the reimagined future set forth in the special issue of JAMDA is an aspirational future. And, when changes are effected, they will likely be incremental, given the lack of an existing system of long-term care.

Perhaps the more fundamental reason that we’ll forever be reimagining long-term care is that care and outcomes can never be optimal regardless our best efforts. Ultimately, care recipients face significant physical and/or cognitive challenges, have often lost their closest partner owing to death, and may have complex conditions and symptoms with limited life expectancy. Given these realities of the population served, how can we

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Within the next few months, the National Academies of Sciences, Engineering, and Medicine is expected to release recommendations to improve the quality of nursing home care, presumably with relevance to other long-term care settings. It is hoped that their report and the articles in the special issue of JAMDA combine with the renewed national focus on the future of long-term care to spur constructive change.

References