International Journal of Gerontology 20 (2026) 87–88
https://doi.org/10.6890/IJGE.202604_20(2).EC3

International Journal of Gerontology

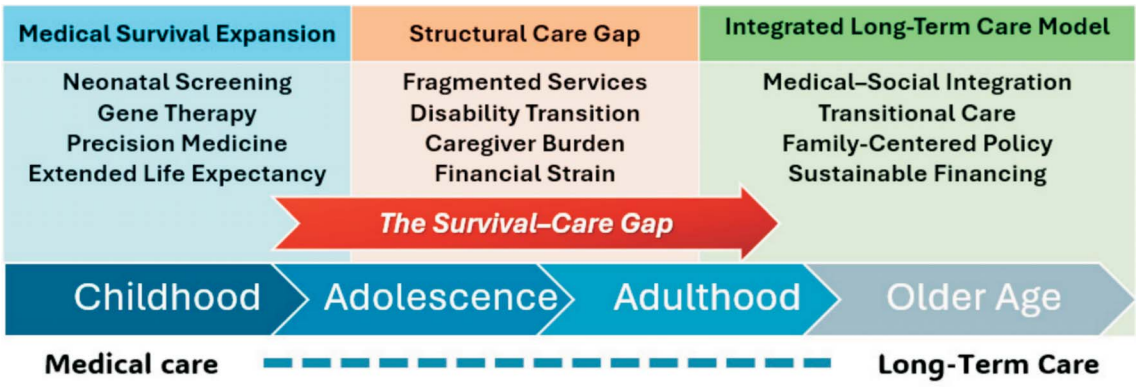
journal homepage: http://www.sgecm.org.tw/ijge/

Editorial Comment

Long-Term Care Policy for Rare Diseases in an Aging Society: From Survival to Sustainable Care

Shu-Feng Lin [a], Lan-Ping Lin [b], Jin-Ding Lin [c *]

[a] *Graduate Institute of Life Sciences, College of Biomedical Sciences, National Defense Medical University, Taipei, Taiwan,* [b] *School of Medicine, College of Medicine, National Defense Medical University, Taipei, Taiwan,* [c] *Graduate Institute of Long-Term Care, College of Health and Welfare, MacKay Medical University, New Taipei City, Taiwan*



The Survival–Care Gap Framework in Rare Disease Long-Tern Care Policy

Central Illustration. Medical advances have transformed many rare diseases from fatal childhood conditions into lifelong chronic disorders. While survival has improved substantially, long-term care systems have lagged biomedical innovation. This conceptual framework illustrates the resulting "survival–care gap," emphasizing the necessity of policy transformation toward integrated long-term care models that address medical, functional, and social needs across the life course.

First Author.
Shu-Feng Lin
Graduate Institute of Life Sciences, College of Biomedical Sciences, National Defense Medical University

Corresponding Author.
Jin-Ding Lin
Graduate Institute of Long-Term Care, College of Health and Welfare, MacKay Medical University
E-mail address:
jack.lin4691@mmu.edu.tw

Traditionally, rare diseases (RDs) policy has focused on catastrophic illness certification, high-cost drug reimbursement, and life-saving interventions. Advances in neonatal screening, molecular diagnostics, and gene therapy have significantly improved the patients' survival. What was once predominantly managed within the confines of acute pediatric care has now evolved into a complex, lifelong journey requiring sustained multidisciplinary care. This epidemiological transition exposes a structural survival–care gap.[1]

Patients with RDs often face a diagnostic odyssey followed by a lifetime of symptom management. RD patients present highly heterogeneous needs that span medical, rehabilitative, psychological, and social domains. Long-term care systems, however, were primarily designed for age-related frailty, dementia, and stroke. They are rarely tailored to early-onset, low-prevalence, high-complexity disorders. Unlike typical geriatric populations, RD patients often require technologically advanced care, rehabilitation across developmental stages, and caregiver-intensive support beginning in childhood. The mismatch between disease trajectory and service design results in fragmented transitions between pediatric and adult services, limited community-based rehabilitation resources, and heavy reliance on informal family caregiving.[1,2]

The caregiver burden in RDs is substantial and persistent. Families with RD patients reported significantly higher financial stress, employment disruption, and psychological distress.[3,4] Moreover, because expertise in RDs is often concentrated in tertiary centers, geographic disparities can limit access to specialized care. Without coordinated long-term planning, medical breakthroughs may prolong survival without corresponding improvements in quality of life.[5]

The World Health Organization (WHO) introduced the Innovative Care for Chronic Conditions (ICCC) framework in 2002 to guide health systems in shifting from fragmented disease services toward integrated, patient-centered models of care. The framework emphasizes coordination across macro-level policy environments, meso-level healthcare organizations, and micro-level community and family systems, supported by multidisciplinary collaboration, patient self-management, and community resource integration.[6] These principles closely align with emerging policy paradigms in RD governance, which increasingly emphasize continuity of care and long-term support rather than episodic medical treatment.[7]

Comparative experiences in East Asia provide instructive policy insights. Japan's Intractable Disease Act (Nanbyo) offers a comprehensive framework that combines medical subsidies with community-based social services, with particular attention to maintaining the stability of patients' living environments.[8] South Korea has also advanced its policy framework through the Rare Disease Management Act, gradually expanding social welfare coverage and strengthening support mechanisms for affected families.[9] Taiwan, meanwhile, was the first country in Asia to enact dedicated RD legislation through the Rare Disease Prevention and Medicine Act, which ensures access to orphan drugs and specialized nutritional supplements through National Health Insurance (NHI) financing. Taiwan's policy infrastructure also benefits from its centralized NHI database and the institutional maturity of the Long-Term Care 2.0 system.[10] However, the integration of individuals with RDs into the broader long-term care framework remains incomplete. As medical advances continue to extend survival, the need for stronger cross-sector policy alignment between healthcare and long-term care systems becomes increasingly urgent. These comparative experiences underscore the broader policy transition required in aging societies: moving beyond survival-oriented medical systems toward integrated models capable of sustaining lifelong care.

RD policy in aging societies must move beyond a "one-size-fits-all" approach toward a model of precision long-term care that recognizes the heterogeneous and lifelong needs of patients. In light of Taiwan's evolving health and long-term care reforms, our analysis identifies three strategic pillars for future policy development. First, integrated transitional care models are needed to bridge pediatric and adult healthcare systems, ensuring continuity of care across the life course. Second, standardized assessment frameworks that capture multidimensional needs — including medical, functional, psychological, and social domains — are essential to guide equitable and needs-based resource allocation. Third, sustainable financing mechanisms should adopt a life-course perspective, shifting from episodic reimbursement models — designed for discrete medical encounters — toward long-term support structures that reflect the enduring nature of RDs.

In super-aged societies, RDs represent a critical test of health system resilience. They expose the structural limits of fragmented governance and highlight the urgency of integrating medical care with long-term social support. As therapeutic innovation continues to expand survival horizons, policy frameworks must evolve accordingly to sustain the quality and continuity of care across the lifespan. The next frontier of rare disease policy is therefore not simply extending life, but ensuring that longer lives are supported by systems capable of sustaining dignity, participation, and care throughout the life course.

Conflicts of interest

All authors declare no conflicts of interest.

References

1. Adachi T, El-Hattab AW, Jain R, et al. Enhancing equitable access to rare disease diagnosis and treatment around the world: a review of evidence, policies, and challenges. *Int J Environ Res Public Health.* 2023;20(6):4732. doi:10.3390/ijerph20064732
2. EURORDIS-Rare Diseases Europe. *The voice of 12,000 patients. Experiences and expectations of rare disease patients on diagnosis and care in Europe*. EURORDIS-Rare Diseases Europe; 2009. Accessed February 28, 2026. https://reurl.cc/R218Dn
3. Atkins JC, Padgett CR. Living with a rare disease: psychosocial impacts for parents and family members – a systematic review. *J Child Fam Stud.* 2024;33(2):617–636. doi:10.1007/s10826-024-02790-6
4. Yang G, Cintina I, Pariser A, Oehrlein E, Sullivan J, Kennedy A. The national economic burden of rare disease in the United States in 2019. *Orphanet J Rare Dis.* 2022;17(1):163. doi:10.1186/s13023-022-02299-5
5. Claessens Z, Vanneste A, Van Isterdael C, Verbeke C, Wens I, Huys I. Criteria to evaluate unmet health-related needs of persons living with rare diseases and their caregivers: rapid literature review and stakeholder consultations. *Orphanet J Rare Dis*. 2025;20(1):321. doi:10.1186/s13023-025-03838-6
6. World Health Organization. *Innovative care for chronic conditions: building blocks for actions*. World Health Organization; 2002. Accessed March 5, 2026. https://www.who.int/publications/i/item/innovative-care-for-chronic-conditions-building-blocks-for-actions
7. Gentilini A, Neez E, Wong-Rieger D. Rare disease policy in high-income countries: an overview of achievements, challenges, and solutions. *Value Health.* 2025;28(5):680–685. doi:10.1016/j.jval.2024.12.009
8. Uchida T, Takahashi Y, Yamashita H, et al. Evaluation of clinical practice guidelines for rare diseases in Japan. *JMA J.* 2022;5(4):460–470. doi:10.31662/jmaj.2022-0094
9. Moon J. Understanding and managing patients with adult rare diseases. *J Genet Med.* 2024;21(1):1–5. doi:10.5734/JGM.2024.21.1.1
10. Hsiang NC, Huang WF, Gau CS, Tsai TW, Chang LC. The impact of the rare disease and Orphan Drug Act in Taiwan. *J Food Drug Anal.* 2021;29(4):717–725. doi:10.38212/2224-6614.3383