

International Journal of Population Data Science

Journal Website: www.ijpds.org



Conducting a National, Longitudinal Examination of Dual-Role Caregiving and Developing Reusable Analytical Tools to Facilitate Research using CLSA Data

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Background

Family caregivers experience substantial burden and distress, yet longitudinal evidence is scarce, particularly for individuals concurrently providing and receiving care (“dual-role caregivers”) who may face compounded vulnerability. The Canadian Longitudinal Study on Aging (CLSA) offers a population-based opportunity which we leveraged to conduct a longitudinal study of dual-role caregiving. In parallel, we developed an R package to improve efficiency and transparency of all CLSA-based research.

Method

We classified CLSA participants at each study cycle as caregivers-only, care-recipients-only, dual-role caregivers, or neither caregiving/care-receiving, and visualized role transitions using a Sankey diagram. We compared socio-demographics, caregiving activities, health measures, and satisfaction with life (SWL) between caregivers-only and dual-role caregivers. The R package contains three core components: 1) harmonization of missing/invalid values across cycles; 2) automated data quality assessments; 3) creation of derived variables (e.g., caregiving/care-receiving flags; composite outcome measures).

Results

At baseline, 19,551/51,169 participants provided care, of whom 13.9% were dual-role caregivers – this increased to 19.5% by Follow-Up2. Compared with caregivers-only, dual-role caregivers were more often female, had lower income, poorer health, lower SWL, and greater functional impairments. While providing substantial care, dual-role caregivers also required considerable support, including informal and professional personal care (22% and 11%, respectively) and medical care (15% and 30%, respectively). Functional decline at subsequent cycle was more common among dual-role caregivers (14.5%) than caregivers-only (7.5%).

Discussion

Our study highlights that dual-role caregivers are increasingly prevalent and experience heightened vulnerabilities. The accompanying R package provides a scalable, transparent resource to support future CLSA research.

