The role of carer burden and caregiving contexts in dementia rehabilitation: Implications for program design and tailored support

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KEY TAKEAWAY

- **Higher subjective carer burden has longer-term impacts** on the health and well-being of both carers and their care recipients with dementia within the rehabilitation context.
- Subjective carer burden is a key factor in shaping rehabilitation success and should be carefully assessed and addressed.
- **Extended family carers** (vs. spouses/partners) were associated with poorer care recipient well-being (**depression, QoL**), highlighting the need for tailored support in dementia rehabilitation.

BACKGROUND

Informal carers are often seen as collaborative partners in dementia care, yet little is known about how broader caregiving contexts, particularly subjective carer burden, relate to the health and well-being of carers and their care recipients with dementia receiving rehabilitation.

AIM

To examine how broader caregiving contexts are associated with health and well-being outcomes for care dyads within dementia rehabilitation, both at baseline and over time (12 months).

METHODS

Study design

Cross-sectional & Longitudinal studies

Data source

Secondary analysis of Interdisciplinary Home-bAsed Reablement Program (I-HARP) (Jeon et al., 2025)

- A multicentre pragmatic RCT for community-dwelling people with dementia and their carers in Sydney, Australia

Key baseline participants' characteristics

130 dementia care dyads at baseline (116 dyads at 12-month follow-up)

- **Carers:**
  - Mean age 66.8 years (SD 13.4); 70.8% female
  - 54.6% spouse/partner carers, 34.6% adult child carers
  - 80.8% co-residing
  - 23.1% had additional caring responsibilities
  - 54.6% were sole carers
  - 66.2% were in non-paid employment (e.g., fully retired)
  - Average caregiving time: 88.6 hours/week (range: 4-168 hours)
  - Mean carer burden (Zarit Burden Inventory, ZBI): 31.0 (SD 13.4)
- **People with dementia**
  - Mean age 81.4 years (SD 6.6); 58.5% female
  - 56.2% had mild dementia
  - 81.5% had ≥1 comorbid condition(s)

Caregiving context variables

- Co-residence (yes/no)
- Additional caring responsibilities (yes/no)
- Sole carer status (yes/no)
- Carer-care recipient relationship: spouse/partner, adult child, others (e.g., sibling, in-law, friend)
- Caregiving hours/week
- Subjective carer burden (Zarit Burden Inventory, ZBI)

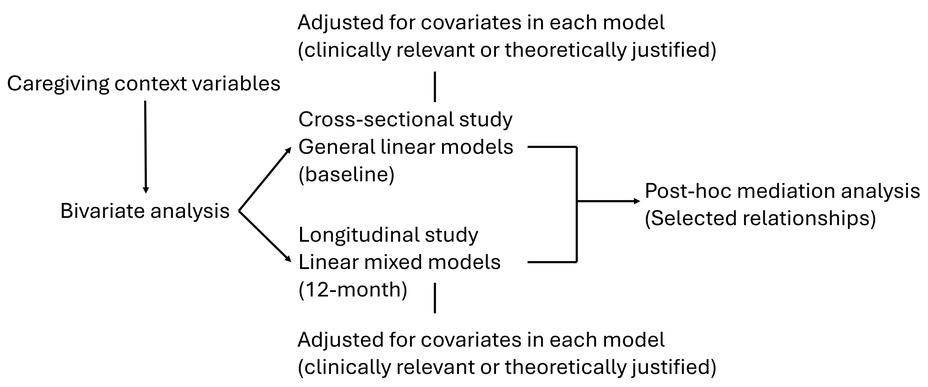
Outcome variables

Care recipients with dementia:

- Functional independence (DAD, Disability Assessment for Dementia)
- Physical functioning (SPPB, Short Physical Performance Battery)
- Depression (CS-GDS-15, Collateral Source version of the Geriatric Depression Scale)
- Self- and proxy-rated quality of life (QoL) (QoL-AD, Quality of life in Alzheimer's Disease)
- Self-rated health-related (HR) QoL (EQ-5D-5L, 5-level version of the EuroQol five dimensions)

Carers: HRQoL (EQ-5D-5L)

Figure 1. Statistical methods



RESULTS

Table 1. Baseline associations between caregiving context variables and outcomes (n = 130 dyads) — regression models with and without carer burden

Outcome	Without ZBI B (95% CI), *p-value*	With ZBI B (95% CI), *p-value*
DAD (Functional ability)	Additional caring −10.73 (−19.67, −1.78), *0.019**	—
	—	Carer burden −0.51 (−0.77, −0.24), < *0.001**
SPPB (Physical functioning)	—	—
CS-GDS-15 (Depression)	Relationship (extended family vs. spouses/partners) 4.61 (2.11, 7.11), < *0.001**	Relationship (extended family vs. spouses/partners) 3.42 (1.11, 5.73), *0.004**
	—	Carer burden 0.12 (0.07, 0.17), < *0.001**
Care recipient QoL-AD (Self-rated quality of life)	Relationship (extended family vs. spouses/partners) −6.05 (−10.09, −2.01), *0.004**	Relationship (extended family vs. spouses/partners) −5.53 (−9.52, −1.54), *0.007**
	—	Carer burden −0.10 (−0.19, −0.02), *0.020**
Proxy QoL-AD (Proxy-rated quality of life)	Relationship (adult children vs. spouses/partners) −3.23 (−5.90, −0.55), *0.019**	—
	Relationship (extended family vs. spouses/partners) −6.51 (−10.10, −2.92), < *0.001**	Relationship (extended family vs. spouses/partners) −5.70 (−9.06, −2.34), *0.001**
	—	Carer burden −0.16 (−0.23, −0.08), < *0.001**
Care recipient EQ-5D-5L (HRQoL)	—	Co-residence 0.14 (0.01, 0.27), *0.041**
	—	Carer burden 0.00[a] (−0.01, 0.00[b]), *0.046**
Carer EQ-5D-5L (HRQoL)	—	Carer burden −0.01 (−0.01, 0.00[c]), *0.001***

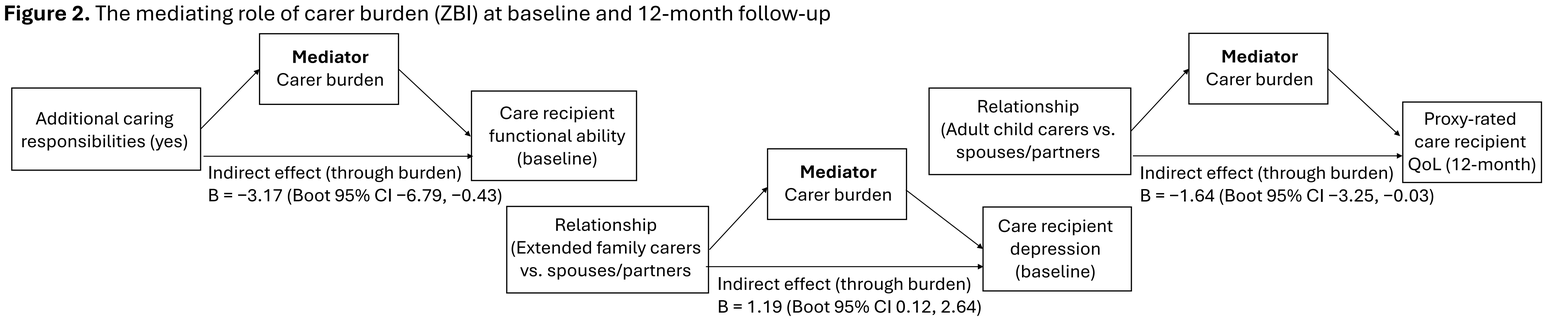
Note. B = Beta coefficients
[a] = −0.003; [b] = −0.00006025; [c] = −0.002
*Adjusted for care recipients' age, gender, education level, number of health condition, and dementia severity
**Adjusted for carers' age, gender, education level, employment status, number of health condition, and care recipients' dementia severity

Table 2. Longitudinal associations between caregiving context variables and outcomes (n = 116 dyads) – linear mixed models with and without carer burden

Outcome	Without ZBI B (95% CI), *p-value*	With ZBI B (95% CI), *p-value*
DAD (Functional ability)	—	Carer burden −0.47 (−0.67, −0.27), < *0.001*[†]
SPPB (Physical functioning)	—	Carer burden −0.03 (−0.06, 0.00[a]), *0.040*[†]
CS-GDS-15 (Depression)	Relationship (extended family vs. spouses/partners) 4.17 (1.84, 6.50), < *0.001*[†]	Relationship (extended family vs. spouses/partners) 3.10 (0.99, 5.20), *0.004*[†]
	—	Carer burden 0.13 (0.09, 0.17), < *0.001*[†]
Care recipient QoL-AD (Self-rated quality of life)	—	Carer burden −0.17 (−0.24, −0.09), < *0.001*[†]
Proxy QoL-AD (Proxy-rated quality of life)	Relationship (adult children vs. spouses/partners) −2.44 (−4.77, −0.11), *0.040*[†]	—
	Relationship (extended family vs. spouses/partners) −4.22 (−7.24, −1.19), *0.006*[†]	Relationship (extended family vs. spouses/partners) −3.60 (−6.39, −0.80), *0.012*[†]
	—	Carer burden −0.18 (−0.23, −0.13), < *0.001*[†]
Care recipient EQ-5D-5L (HRQoL)	—	Carer burden 0.00[b] (−0.01, 0.00[a]), *0.002*[†]
Carer EQ-5D-5L (HRQoL)	—	Carer burden −0.01 (−0.01, 0.00[c]), < *0.001*[‡]

Note: B = Beta coefficients
[a] = −0.002; ; [b] = −0.004; [c] = −0.003
[†] Adjusted for group (intervention vs. control), time, care recipients' age, gender, dementia severity, education level, and number of health conditions
[‡] Adjusted for group (intervention vs. control), time, carers' age, gender, education level, employment status, number of health conditions, and care recipients' dementia severity

Figure 2. The mediating role of carer burden (ZBI) at baseline and 12-month follow-up



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