Factors associated with family caregiver burden of home-dwelling patients with advanced dementia

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Background

Family caregivers of home-dwelling patients with advanced dementia experience a high level of caregiving burden due to the extensive level of care required by patients over a prolonged period of time.(1) They often have to make decisions on patients' behalf despite feeling ill-equipped.(2) At the advanced stage, patients' susceptibility to recurrent infections predisposes them to repeated hospitalisations which fragment care and incur substantial healthcare costs.(3) Consequently, family caregivers may have difficulty coping, resulting in patients' admission to long-term care facilities for end-of-life care,(4) rendering preferences for home death unattainable.(5) The limited evidence exploring family caregiver burden of home-dwelling patients with advanced dementia has resulted in a rudimentary understanding of their needs and the interventions required for sustaining them in their caregiving journey at home. Without interventions, the chronic stress and burden experienced could affect family caregivers' physical health, psychological well-being, and quality of life, with substantial societal and opportunity costs incurred.(1)

Aims

Primary aim: To identify factors associated with family caregiver burden of home-dwelling patients with advanced dementia. **Secondary aim:** To examine the relationship between baseline caregiver burden and treatment decisions made at the end of life.

Methods

Study design: Prospective cohort study. **Sampling approach:** Convenient sampling of patient-family caregiver dyads enrolled in a home-based palliative care programme dedicated for patients with advanced dementia.(6) **Inclusion criteria:** Family caregivers ≥ 21 years of age with caregiver burden assessed on enrolment with the Zarit Burden Interview (ZBI).

Data source: Routine documentation extracted from the electronic medical records. **Independent variables:** Sociodemographic information, informal paid help availability, community resources utilised, care plans established on enrolment, dementia aetiology & stage, comorbidities, clinical phase (AN-SNAP), symptom severity & QoL (PAINAD, NPI-Q, MNA & QUALID for stable patients; CAD-EOLD for dying patients). **Dependent variable:** Family caregiver burden (ZBI) (ZBI score ≥24 → at risk of depression).

Other data collected from a purposive sample of deceased patients: Place of death, receipt of CPR, antibiotics use, laboratory investigations performed & enteral feeding tube insertion in the last 2 weeks of life. **Analysis:** Bivariate analysis using Spearman Rho correlation, Mann-Whitney U (2-categorical) and Kruskal-Wallis (multi-categorical) tests with post-hoc analysis. Except for variables with multicollinearity, statistically significant & clinically relevant variables were shortlisted for multivariate analysis using multiple linear regression (continuous ZBI scores as outcome) and binomial logistic regression (ZBI scores dichotomised into </≥24 as outcome).

Results

From Oct 2014 to Dec 2020, N=377:

Patients: Median age 88 (IQR 84-93) years, 72.4% females, 70.6% widowed, 85.9% Chinese, 31.0% had Alzheimer's disease with median duration of diagnosis of 6 (IQR 4-9) years.

Family caregivers: Median age 58 (IQR 53-64) years, 85.9% were children of patients, 73.5% lived with patients, 92.3% had informal paid help, median ZBI score 25 (IQR 15-36), indicating mild-moderate burden, 54.4% were at risk of depression.

Compared to patients whose caregivers did not complete the ZBI (N=84), patients whose caregivers did had better nutritional status [MNA: 3 (IQR 1-5) vs 2 (IQR 1-4), p=0.025] and were more comfortable [CAD-EOLD: 37 (IQR 34-40) vs 34 (IQR 30.5-36.5), p=0.005]. A greater proportion were stable (61.5% vs 48.8%, p=0.001), and had care plans established on enrolment (94.2% vs 86.9%, p=0.036).

Table 1 Multivariate Analysis of Factors Associated with Family Caregiver Burden

	Multiple linear regression		Binomial logistic regression	
Variables	**β (95% CI)**	**P-value**	**OR* (95% CI)**	**P-value**
Family caregiver age (reference:† ≥60 years)	-0.22 (-0.38 - -0.07)	0.005	2.13 (1.33 - 3.43)	0.002
Informal paid help availability (reference:† With help)	-9.04 (-14.86 - -3.22)	0.002	2.50 (1.03 – 6.09)	0.044
Community resources utilised prior to enrolment (reference:† Not utilised)	-0.04 (-1.02 – 0.95)	0.943	1.24 (0.75 - 2.05)	0.393
Pneumonia in the past 1 year (reference:† No pneumonia)	2.87 (-0.57 – 6.31)	0.102	1.40 (0.84 - 2.34)	0.197
Congestive cardiac failure (reference:† No congestive cardiac failure)	4.61 (-1.32 – 10.54)	0.127	2.10 (0.80 - 5.49)	0.130
AN-SNAP Phase (reference:† AN-SNAP Phase 1)	0.53 (-1.15 – 2.21)	0.534	1.80 (1.03 - 3.12)	0.038
NPIQ-severity (reference:† NPI-Q score <4)	0.49 (0.08 – 0.89)	0.018	1.17 (0.72 – 1.89)	0.520

AN-SNAP: Australian National Sub-acute and Non-Acute Patient classification system classifies patients into 4 phases based on their condition. Phase 1 denotes stability while phases 2, 3 and 4 indicate that the patient is unstable, deteriorating and terminal respectively; NPI-Q: Neuropsychiatric Inventory Questionnaire is a 12-item tool used for measuring the severity of neuropsychiatric symptoms. Each item is scored on a 3-point scale with a higher score indicating greater symptom severity.
*Odds of having a ZBI score ≥24, indicating risk of depression.
†Reference category for the interpretation of results from binomial logistic regression.

For the 289 patients who passed away, family caregiver burden on enrolment was not associated with the place of death, receipt of CPR, antibiotics used, laboratory investigations performed, and enteral feeding tube insertion (all p>0.05).

Discussion

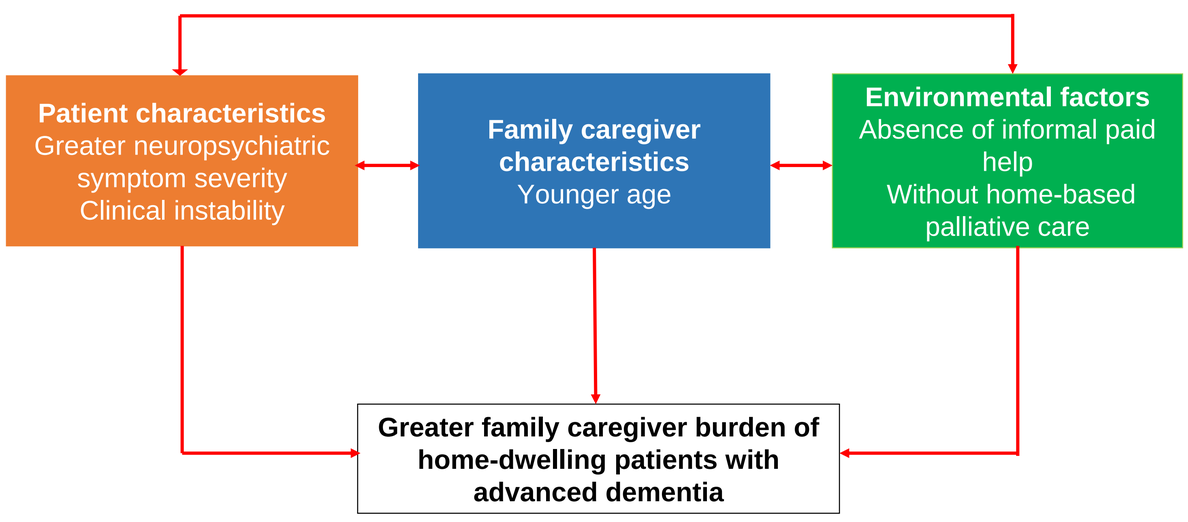

Figure 1. Factors associated with family caregiver burden of home-dwelling patients with advanced dementia.

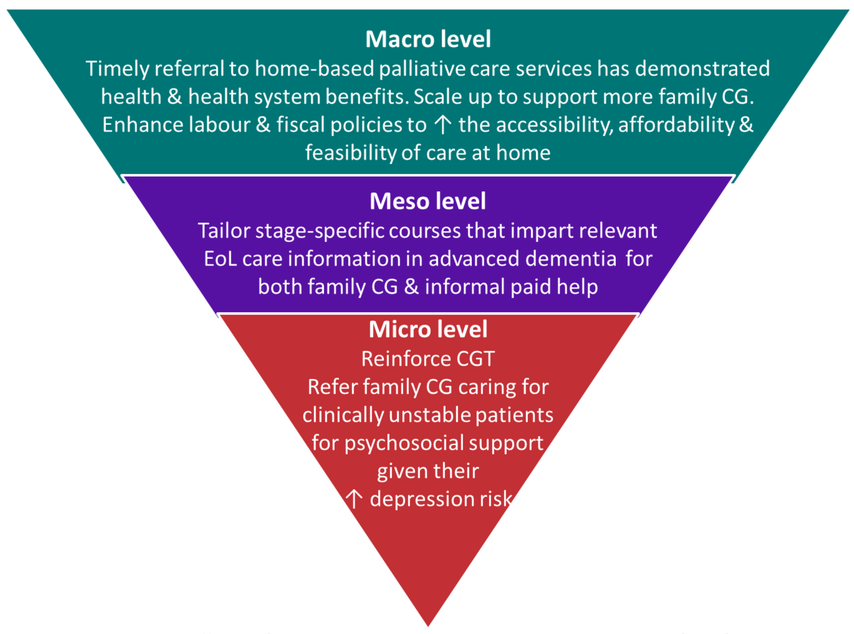

Figure 2. Implications at the macro, meso and micro levels.

Limitations

Causal links could not be established from associations. Using a global ZBI score may oversimplify the interpretation as caregiver burden is a multi-dimensional construct(7, 8) Generalisability of outcomes is limited to settings with similar socioeconomic & healthcare structures. Selection bias is likely as caregivers who completed the ZBI were caring for more comfortable & stable patients and had care plans established. Using routinely collected data restricted the variables available for investigation.

Conclusions

The multi-faceted complexity of end-of-life dementia caregiving in the home setting requires the collective & cohesive collaboration of relevant national agencies & stakeholders. As dementia prevalence increases exponentially with population ageing, instituting these policies & practices early to holistically support family caregivers is imperative, such that satisfying home death preferences will not be just a rhetoric. Future studies could consider characterising the longitudinal evolvement of family caregiver burden along the advanced illness trajectory so that specific interventions at different points can be developed to sustain family caregivers in their care of patients with advanced dementia at home until the end of life.

Acknowledgements: We would like to thank our patients and family caregivers for giving us the opportunity to participate in their care, and the Dover Park Hospice home-based palliative care team for their professional care.

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