

## Trajectories of Burden or Benefits of Caregiving Among Informal Caregivers of Older Adults: A Systematic Review

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### ADMINISTRATIVE INFORMATION

**Support** - Personal source.

**Review Stage at time of this submission** - Data analysis.

**Conflicts of interest** - None declared.

**INPLASY registration number:** INPLASY2023100093

**Amendments** - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 30 October 2023 and was last updated on 21 September 2024.

### INTRODUCTION

**Review question / Objective** How do caregiving burden and benefits change over time among informal caregivers caring for older adults?

**Condition being studied** Informal caregivers often experience multidimensional burdens because of caregiving to functionally disabled older persons such as lack of family support, schedule disruption, or perceived poor health, while they also gain multifaceted benefits from caregiving such as feeling confident, feeling appreciated, or strengthening their relationship to care recipients. Caregiving burden and caregiving benefits are shown to be not mutually exclusive but represent two distinct domains that co-shape caregiving experiences among informal caregivers of older adults with functional limitations. Understanding

how caregiving burden and caregiving benefits co-shape caregiving experiences longitudinally among informal caregivers can capture a comprehensive picture of caregiving experiences. Delineating the longitudinal trajectory shapes of caregiving burden and caregiving benefits may also notify the proper time for interventions to either reduce caregiving burden or improve caregiving benefits among informal caregivers of older adults with functional limitations. Besides, identifying modifiable factors associated with beneficial or burdensome caregiving experience trajectories can be used as targets for intervention development among informal caregivers of older adults with functional limitations.

### METHODS

**Search strategy** We will search for five bibliographic databases - Medline (PubMed),

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Embase, CINAHL, PsycINFO, and The Social Science Database (ProQuest) from inception to 22nd August 2024, without restriction on languages and publication types. Search terms consists of subject headings provided in each database and keywords (only being used for title and abstract searching) related to "informal caregivers", "older care-recipients", "caregiver health-related measures", and "longitudinal studies".

**Participant or population** Participants is defined as informal caregivers of older adults, who provide unpaid care for a person with chronic disease or disability, with care-recipients being non-institutionalized older adults, aged 60 or above. No additional restrictions will be placed on the types of illness and disability of the care-recipients.

**Intervention** NA.

**Comparator** NA.

**Study designs to be included** We will include longitudinal observational studies with data collected from the same participants at three or more time points.

**Eligibility criteria** The outcomes of interests should be measured by caregiving-specific measures assessing the perceived impact of caregiving on caregiver physical, psychological, and social well-being. Eligible studies should be written in English and published on a peer-review journal. Longitudinal studies with three or more time points will be included to identify more complex trajectories over time than studies with only two time points.

**Information sources** Electronic databases: Medline, Embase, CINAHL, PsycINFO, Social Science Database.

**Main outcome(s)** Caregiving burden; Caregiving benefits.

**Quality assessment / Risk of bias analysis** The scale is designed to evaluate the risk of bias across nonrandomized studies in systematic reviews and allows for modifications. The modified version used in the context of this review comprised three domains: 1) Selection (3 items), which evaluates the representativeness of study sample for informal caregivers and care-recipients; 2) Comparability (1 item), which examine if delineating trajectories of burden and benefits controlled for covariates; and 3) Outcomes (4 items), which evaluate the quality of burden and

benefits measures, the explanation of lost to follow-up of study cohort, and the statistical adequacy for delineating trajectories of burden and benefits and identifying associated factors. For each study, each item is scored as 0 or 1, and all items are summed to generate a total score (range: 0-8), with a higher score indicating a lower risk of bias. Studies will be not excluded based on the risk of bias assessment.

**Strategy of data synthesis** We will use narrative synthesis.

**Subgroup analysis** NA.

**Sensitivity analysis** NA.

**Language restriction** Studies written in English will be included.

**Country(ies) involved** Singapore (DukeNUS Medical School).

**Keywords** informal caregivers, caregiving burden, caregiving benefits, older adults.

**Contributions of each author**

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