

Do Existing Caregiver Assessments Measure What’s Important to Caregivers?

Kaelyn Rupinski (BS)¹, Gavin Dickie (MSc)¹, James Piercy (PhD)², Jonathan DeCourcy (BSc)², Victoria Higgins (BA Hons)², Lily Settel (MPH)¹, Nina Sankriti Kumar (BA)¹, Maggie McConnell (MMS)¹, Alan Shields (PhD)¹, Leighann Litcher-Kelly (PhD)¹

¹ Adelphi Values, Boston, MA, USA; ² Adelphi Real World, Bollington, UK

Background and Objectives

- > Stakeholders are increasingly interested in capturing perspectives of both care recipients and caregivers.
- > Currently, there is a potential gap in understanding how well caregiver outcome tools assess experiences considered important and relevant to the experience of caregiving.
- > The aim of this study was to identify, review, and document existing caregiver assessments to determine the extent to which they comprehensively measure caregiver burden across key impact domains and concepts, based on the results of a previously conducted concept-focused literature review (see poster PCR66 for details).

Methodology

Identification of assessments

- Caregiver assessments were identified as part of a targeted literature search (August 2024) using Ovid MEDLINE, PsycINFO, and Embase databases.
- These were supplemented with searches in Google Scholar and the PROQOLID database, to identify any additional relevant assessments.

Selection of assessments

- A list of questionnaires assessing the burden of caring for individuals directly from caregivers was compiled, and assessments were selected for review and evaluation based on frequency of report within the literature.
- Generic caregiver assessments were prioritized over disease-specific assessments, to focus on instruments that assessed a range of burdens and impacts that may be applicable across different types of caregivers (e.g., parents caregiving for children, adults caregiving for spouse, etc.).

Review and evaluation of assessments

- Information on each questionnaire’s development, structure, and conceptual coverage were extracted.
- Conceptual coverage was evaluated against 114 key caregiver impact concepts across 18 unique domains (as identified in a previous concept-focused literature review – see **Table 1** and poster PCR66 for details).
- The total number of concepts that were directly measured by each questionnaire were calculated, to understand the overall conceptual coverage of each selected questionnaire.

Table 1: Caregiver burden domains identified from literature review

Caregiver burden domains identified (N=18)	Impact concepts identified within domain (N=114)
Emotional function	n=25
Caregiver responsibilities	n=16
Adaptive behaviors	n=8
Other family/friend relationships	n=8
Work/school impacts	n=8
Physical function	n=7
Positive impacts	n=7
Social activities	n=6
Financial burden	n=5
Household chores and responsibilities	n=5
Healthcare responsibilities	n=4
Independence	n=3
Self-image	n=3
Spouse/partner relationships	n=3
Recreation/leisure activities	n=2
Sexual function	n=2
Cognitive function	n=1
Sleep	n=1

Table 2: Caregiver questionnaire review and mapping of questions to key caregiver burden domains and impact concepts

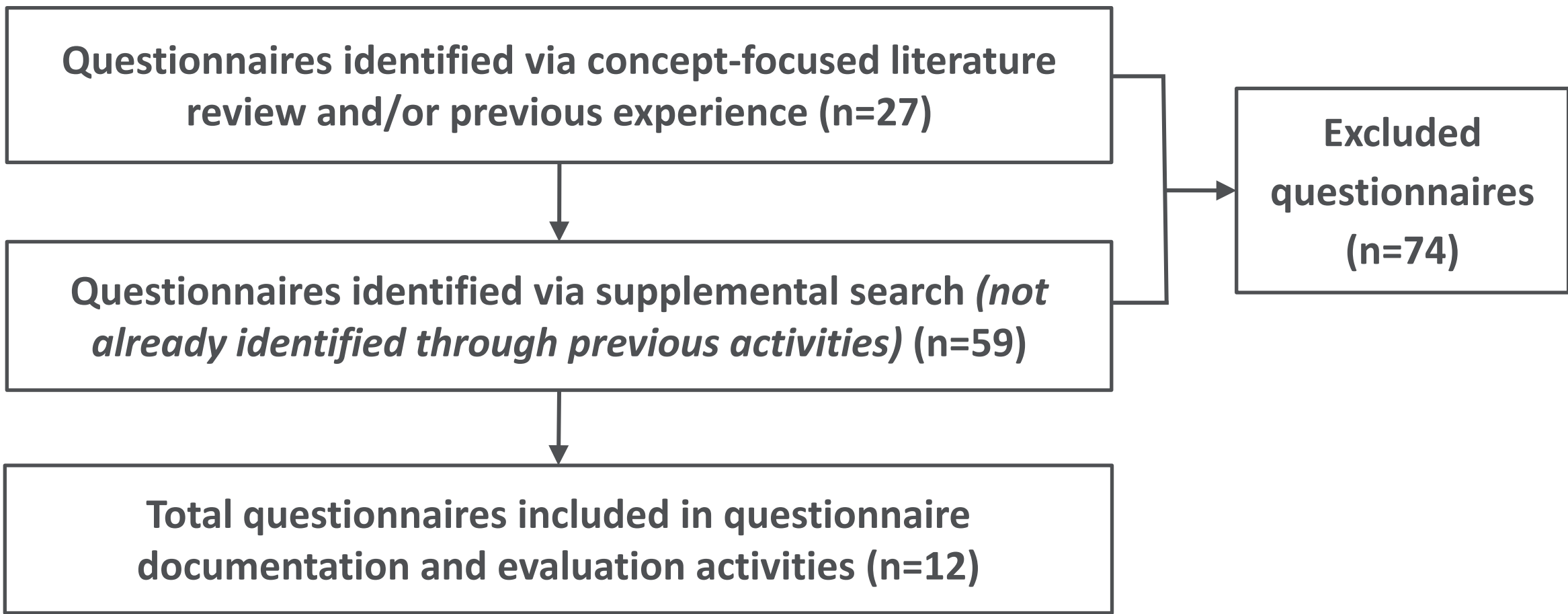
Caregiver questionnaire	Target respondent and context	Caregiver burden domains assessed n/18 (%)	Impact concepts assessed n/114 (%)
Caregiver Burden Inventory ¹ (24 items)	Caregivers of confused or disoriented older people	10 (55.6%) caregiver responsibilities, emotional function, household chores/responsibilities, independence, other friend/family relationships, physical function, sleep, social activities, spouse/partner relationships, work/school impacts	15 (13.2%)
Caregiver Self Assessment Questionnaire ² (18 items)	Family caregivers of chronically ill older adults as a clinical screener	8 (44.4%) cognitive function, emotional function, independence, other family/friend relationships, physical function, self image, sleep, work/school impacts	10 (8.8%)
Parkinsonism Carers Quality of Life ³ (26 items)	Caregivers of patients with atypical Parkinsonism in clinical and research settings	7 (38.9%) caregiver responsibilities, emotional function, other family/friend relationships, physical function, self image, sleep, social activities	17 (14.9%)
Burden Scale for Family Caregiver ⁴ (28 items)	Clinical practice or research with family members who care for patients at home (includes dementia and non-dementia caregiver items)	7 (38.9%) caregiver responsibilities, emotional function, financial burden, other friend/family relationships, physical function, positive impacts, self-image	16 (14.0%)
Caregiver Reaction Assessment ⁵ (24 items)	Family members caring for elderly people with physical and mental impairments	7 (38.9%) caregiver responsibilities, financial burden, other family/friend relationships, physical function, positive impacts, self-image, work/school impacts	14 (12.3%)
Functional Assessment of Cancer Therapy - General – Caregiver ⁶ (27 items)	Family members of cancer patients as a screening assessment	7 (38.9%) emotional function, other friend/family relationships, physical function, positive impacts, sexual function, sleep, work/school impacts	11 (9.6%)
Caregiver Strain Index ⁷ (13 items)	Caregivers of elderly family members as a clinical screening assessment of caregiver strain	7 (38.9%) caregiver responsibilities, emotional function, financial burden, physical function, self-image, sleep, work/school impacts	8 (7.0%)
Brief Assessment Scale for Caregivers ⁸ (14 items)	Caregivers of patients with chronic illness in a clinical setting	5 (27.8%) emotional function, household chores/responsibilities, other family/friend relationships, positive impacts, self-image	9 (7.9%)
Zarit Burden Interview ⁹ (22 items)	Caregivers of elderly persons with dementia	6 (33.3%) caregiver responsibilities, emotional function, financial burden, physical function, self-image, social activities	9 (7.9%)
Quality of Life on Seven Burden Dimensions ¹⁰ (7 items)	Informal caregivers in the context of economic evaluations and healthcare decision making	6 (33.3%) emotional function, financial burden, household chores/responsibilities, other family/friend relationships, positive impacts, work/school impacts	7 (6.1%)
Screen for Caregiver Burden ¹¹ (25 items)	Caregivers of a spouse with Alzheimer's disease in a research or clinical setting	4 (22.2%) emotional function, financial burden, household chores/responsibilities, physical function	7 (6.1%)
Quality of Life Enjoyment and Satisfaction Questionnaire Short Form ¹² (14 items)	Patients with anxiety or affective disorders	2 (11.1%) recreation/leisure activities, work/school impacts	2 (1.8%)

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Results

Figure 1: Identification of caregiver questionnaires



- > A total of 12 questionnaires, assessing caregiver burden, were selected for inclusion (**Figure 1**), based on frequency of report and the content of the questionnaire itself (e.g., if questionnaire measured concepts not measured by other identified questionnaires).
- > No questionnaire measured all 18 caregiver burden domains identified in the literature, and only the Caregiver Burden Inventory measured ≥50.0% of the domains (**Table 2**).
- > The caregiver burden domains most frequently measured by the 12 questionnaires were emotional function (measured by 10 questionnaires), physical function (measured by 9 questionnaires), and other family/friend relationships (measured by 8 questionnaires).
- > Example domains frequently not assessed by the questionnaires though reported as important to caregivers include impact on autonomy/independence, social activities, and household responsibilities.
- > The three questionnaires that directly measured the most impact concepts were the Parkinsonism Carers Quality of Life (n=17/114, 14.9%), Burden Scale for Family Caregivers (n=16/114, 14.0%), and Caregiver Burden Inventory (n=15/114, 13.2%).
- > None of the questionnaires included items that measured adaptive behaviors or healthcare responsibilities.

Conclusions

- > Results from this review of existing caregiver burden assessments suggest that currently available tools often do not assess the caregiver burden domains and impact concepts considered relevant and important to caregivers.
- > As such, the collection and understanding of caregiver’s perspectives in research is potentially limited and missing aspects of caregiver burden important to the experiences of caregiving.
- > There is a need for a new tool to capture the universal burden of caregiving, which can quantify burden agnostically across different types of care recipients and caregivers.

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