

# BMJ Open Instruments in general practice to identify and to measure (over)burden due to informal care for caring relatives: a scoping review protocol

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## ABSTRACT

**Introduction** Family caregivers provide by far the largest share of long-term, unpaid care for their primarily elderly and chronically ill relatives or friends. This is associated with a higher risk of psychological and physical overload for the caregivers due to the persistently high time, financial and emotional burden.

Recognising the effects of persistent burden on caring relatives at an early stage significantly contributes to the appropriate coordination of available resources and mediation of individual support to maintain a functional caring relationship without excessive demands. General practitioners are usually responsible for the early detection of burden arising from informal care and the coordination of adequate measures. The objective of this review is to give an overview of instruments to identify and measure (over)burden of caring relatives in German general practice and to describe their characteristics.

**Methods and analysis** We used the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist in addition to the Joanna Briggs Institute Reviewer's Manual to describe the aims and methods of the planned scoping reviews. This protocol has been registered with Open Science Framework (OSF), <https://osf.io/9ce2k>. Two reviewers will run the search to identify studies in four databases (PubMed, LIVIVO, the Cochrane Library and CINAHL) in June and July 2023. Abstracts, titles and full-text publications will be screened to extract data from each included study using a data extraction form. Additionally, an overview of all studies including main study characteristics and detailed information on identification instruments will be given to map the different instruments and tools and to clarify statements concerning their use and practicability in general practice.

**Ethics and dissemination** Ethical approval or consent to participate is not required, as data in this study consists of published studies and not individual data from human or animal participants. Dissemination will consist of publications, presentations and other knowledge translation activities.

## INTRODUCTION

Early identification, intervention and coordination of adequate measures may help to prevent negative health effects due to burden

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Our review addresses a topic of great public health importance, as early and structured identification of caring relatives in general practice can improve patient health, the work of primary care professionals and the healthcare system.
- ⇒ To our knowledge, this will be the first scoping review to analyse which instruments general practitioners use to identify caring relatives in general practice; knowledge gaps in existing studies will also be identified.
- ⇒ The search strategy includes four electronic databases with peer-reviewed literature and is based on a tailored search strategy, which has been iteratively refined to retrieve as many relevant published studies as possible.
- ⇒ Due to the breadth of the studies included, the final data extraction framework will not be finished until the review is done.
- ⇒ A limitation is that only publications in German, English and French are included.

caused by providing informal care.<sup>1–3</sup> An increasing level of informal carers' burden is an important factor because it determines to a large extent various outcomes such as health, a higher risk of mortality, institutionalisation, caregiving style and abusive behaviour.<sup>4–7</sup> Despite recommendations and existing instruments in general practices that identify carers and their needs, many of them remain unidentified. This situation is aggravated by the fact that informal carers rarely self-identify as such and request support, as they often do not care for their own needs and burden.<sup>8 9</sup> As a result, they remain largely unsupported, which increases the risk for secondary physical and psychological morbidity from caregiving and leads to numerous negative consequences such as declines in physical health, mental health concerns and less quality of life.<sup>8 10</sup> Additionally, caregiving often leads to



financial strain and increased financial costs to the family and the healthcare system.<sup>11</sup> The COVID-19 pandemic also complicated the support of family caregivers and the need for improvements in identification, communication and navigation increased.<sup>12</sup>

The identification of carers is complex and further complicated if, for example, patients and carers are not registered in the same general practice.<sup>8,9</sup> Although the need to identify informal carers at an early stage is well known and has been established in policy and practice for a longer time, the support informal carers receive through general practice is weak.<sup>9,13</sup> Several recent studies conducted by Wangler and Jansky show that the wishes of caregivers regarding an early approach by the general practitioner (GP) practice are frequently not fulfilled. Less than 50% of caregivers (42%) report having been promptly identified by their GP. In only 18% of cases, the responsible GP approached the caregiver proactively.<sup>14</sup> Qualitative interviews Wangler and Jansky conducted with 37 caregivers also stated that they initially feel an uncertainty about whether their needs and problems should be a matter for GP support. This hesitance sometimes leads to problematical situations. The results from these interviews match those of other studies, which showed that early and systematic identification of family carers remains challenging in the daily general practice setting.<sup>8,14</sup>

Some standardised and validated instruments for the identification and recording of care-related burden exist, for example, the Zarit Burden Interview (long/short)<sup>15-17</sup> or the Burden Scale for Family Caregivers (BSFC—short/long), which was originally developed for German-speaking countries.<sup>18-20</sup> The BSFC-s (short version/10 items, long version/28 items) is now available free of charge in over 20 languages ([www.caregiver-burden.eu](http://www.caregiver-burden.eu)).<sup>21</sup> The 10 items of the BSFC-s (short version, see <http://www.caregiver-burden.eu>) are rated on a scale from 0 (strongly disagree) to 3 (strongly agree). The score ranges from 0 to 30 points. Higher scores indicate a greater (subjective) caregiver burden.<sup>18</sup> Although the reliability and validity of the BSFC-s for measuring subjective burden in informal

carers have also been demonstrated, this scale is barely used as a screening instrument in general practice.<sup>7,20</sup>

For this reason, we intend to provide an overview of existing instruments with a focus on their actual use in general practice. In addition, characteristics of successfully implemented instruments are summarised to give recommendations for adaptations.

## METHODS AND ANALYSIS

This protocol uses the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist and the Joanna Briggs Institute (JBI) Reviewer's Manual to describe the objectives, eligibility criteria and methods of the planned scoping review.<sup>22,23</sup> We will conduct a scoping review to gain a better understanding of whether and how existing instruments to identify caring relatives and to measure their burden are used. We will also focus on the characteristics of those instruments and what this means for the implementation in general practice to draw conclusions for improving the implementation and usage of existing instruments. For this scoping review, the Arksey and O'Malley five-stage framework for conducting scoping reviews including the following steps was used: identifying the research question (1), identifying relevant studies (2), study selection (3), charting the data (4) and collating, summarising and reporting the results.<sup>5,23-25</sup>

### Objectives

**Main objective:** What tools are used to assess and identify caregiver burden at an early of caregiving in general practice?

**Secondary objective:** Which factors and characteristics of instruments are associated with a systematic use and successful implementation in general practice as well as barriers limiting the implementation?

### Information sources

To answer our central research questions, we use an iterative search strategy involving the search for data in four electronic databases (PubMed, LIVIVO, the Cochrane

**Table 1** Inclusion and exclusion criteria for eligible studies

	Inclusion	Exclusion
Population	Adult patients in general practices with burden caused to informal care of elder and chronic ill patients.	Patients with known disease-specific health problems similar.
Concept	Any kind of instrument (eg, questionnaire, interview) and reporting format to measure or enable a progress evaluation of burden due to informal care.	
Context	Studies conducted in general practice settings and family practices.	Studies dealing with caring relatives but not describing how these were identified.
Type of studies	Quantitative studies (eg, cross-sectional studies, cohort studies, case-control studies). Qualitative studies (interviews, focus groups, observations, document studies). Mixed-method studies.	Author replies/comments. Study protocols.
Language, time frame	German. English. French. No time frame.	All other languages.

Library, CINAHL) from inception to June and July 2023 and the reference lists of key studies to identify any studies eligible for inclusion. The time period was deliberately not narrowed down in order to completely include recent research and to present the state of knowledge as comprehensively as possible.

### Search

A preliminary search was performed in PubMed using database specific Boolean operators based on the inclusion and exclusion criteria summarised in [table 1](#) using the terms (and their synonyms) 'General Practice' and 'Family carer' and 'identification'. In a second step, a search strategy was developed for PubMed, using the preliminary search terms supplemented by additional terms found in the preliminary search such as specific instruments related to family carers in general practice. This strategy will be adapted to each of the other databases with the support of a librarian. [Table 2](#) shows the preliminary search and the search terms for PubMed.

The reference management tool Citavi will be used for database organisation of the search results retrieved. After that, duplicates will be eliminated.

### Eligibility criteria

Studies will be included if they meet the specified criteria presented in [table 1](#). Studies are required (1) to include

**Table 2** Preliminary search in PubMed and search terms used

#	Query
S10	S1 AND S2 AND S3 AND S4 AND S6
S9	S1 AND S2 AND S4 AND S5 AND S6
S8	S1 AND S2 AND S3 AND S4
S7	S1 AND S2 AND S4
S6	(((((Zarit Burden Inventory) OR (Caregiver Strain Index)) OR (Caregiver Reaction Assessment)) OR (Caregiver Demands Scale)) OR (Appraisal of caregiving Scale)) OR (Burden Scale for Family Caregivers)
S5	(identify) OR (measure)
S4	((burden) OR (care burden)) OR (caregiver burnout)) OR (caregiver exhaustion)
S3	((instrument) OR (screening)) OR (assessment)
S2	((family practice) OR (General Practitioner)) OR (Family Physician)
S1	((family carer) OR (family caregiver)) OR (informal caregiver) OR (spouse caregiver)

adult patients in general practices and (2) to use any kind of instrument or format to identify (over)burdened caring relatives. Due to the team's limited financial and language resources, only articles published in the English, French or German language or with a translation available will be included. This review will include quantitative

Table 3 Data extraction form		
Main information	In detail	
General information	Authors	
	Title	
	Journal	
	Year of publication	
	Objective(s) of the study	Description of the objectives stated
	Type of study	Specifying kind of study, for example, qualitative study, quantitative study, mixed-method-approach
	Study design	Study design as described
	Population	Description of study population in detail (age, gender, specific characteristics)
	Country of origin	
	General practice setting	Single versus multiple physicians, other staff (psychologists, nurses)
Description of instrument/intervention	Type of instrument	Specifying the type(s) of intervention on which the study focuses (eg, questionnaire, interview)
	Description of identification instrument	Characteristics in detail
	Handling of the instrument	Describing how and by whom the tool is delivered (eg, general practitioner, physician, nurse)
	Duration of handling	Time to complete (minutes)
	Type of reporting format	For example, self-reported, examination
Implementation of instrument	Effectiveness (only for comparative studies)	Describing results reported in the study
	Facilitators	Factors enabling the implementation of the instrument as reported in the study
	Barriers	Factors inhibiting the implementation of the instrument as reported in the study

studies (eg, cohort studies, case-control studies and cross-sectional studies) as well as qualitative (eg, interviews, focus groups, observations, document studies) and mixed-method studies focused on the identification of caring relatives/informal carers.

### Selection of sources of evidence

Two reviewers will screen all abstracts and full-text studies in Rayyan (<https://www.rayyan.ai/>). The articles will be screened by title and abstract based on the inclusion and exclusion criteria summarised in [table 1](#). Any articles that are deemed relevant by both reviewers will be included in the full-text review, different judgements will be discussed. In the second step, the two investigators will then each independently assess the full-text articles to determine if they meet the inclusion/exclusion criteria shown in [table 1](#). By using this technique, reference lists of existing primary studies will be checked to ensure the relevant literature appearing in such studies is considered in this study.

### Charting the data

To extract relevant information systematically, a data extraction table in Microsoft Word, based on the JBI Review's Manual, is created. This table ([table 3](#)) contains general and specific information about the studies fulfilling the eligibility criteria for inclusion.<sup>25</sup> Further refinements may be added to include any relevant data that was not initially included during the extraction process. Data from all included studies will then be charted by the first reviewer (YM) and the extraction checked by the second reviewer. The collected data will form the basis of the analysis.

### Synthesis of results

The research questions will be reported as a narrative summary and separately presented in a tabular form. It will be possible to highlight the practical use of the instruments reviewed and identify barriers limiting or impeding their use in daily practice. With a focus on the identification of caring relatives, we will also show areas that have been under-researched and may require further investigation or improvement. We will present results appropriately in an aggregate and visual form using tables and charts.

### Patient and public involvement

No patient involved.

### Ethics and dissemination

As the scoping review methodology is based on the analysis of literature publicly available, ethical approval is not required. It also does not involve medical research or any type of personal confidential information from participants. Findings of the scoping review will be summarised in a structured tabular form containing details on key results and characteristics. The results of this scoping review will be submitted for publication in an international peer-reviewed journal (preferably open access),

scientific meetings and conferences on public health, social medicine and health economics.

**Contributors** Every author has met the following criteria: Substantial contributions to the conception or design of the work; or the acquisition, analysis or interpretation of data for the work. Drafting the work or revising it critically for important intellectual content. Final approval of the version to be published. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

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### REFERENCES

- Bialon LN, Coke S. A study on caregiver burden: stressors, challenges, and possible solutions. *Am J Hosp Palliat Care* 2012;29:210–8.
- Brügger S, Jaquier A, Sottas B. Burdens and coping strategies of informal caregivers. The perspective of informal caregivers. *Z Gerontol Geriatr* 2016;49:138–42.
- Riedel O, Klotsche J, Wittchen H-U. Overlooking informal dementia caregivers' burden. *Res Gerontol Nurs* 2016;9:167–74.
- Hansberry MR, Chen E, Gorbien MJ. Dementia and elder abuse. *Clin Geriatr Med* 2005;21:315–32.
- Yan E, Kwok T. Abuse of older Chinese with dementia by family caregivers: an inquiry into the role of caregiver burden. *Int J Geriatr Psychiatry* 2011;26:527–35.
- Perkins M, Howard VJ, Wadley VG, *et al*. Caregiving strain and all-cause mortality: evidence from the REGARDS study. *J Gerontol B Psychol Sci Soc Sci* 2013;68:504–12.
- Pendergrass A, Malnis C, Graf U, *et al*. Screening for caregivers at risk: extended validation of the short version of the burden scale for family caregivers (BSFC-s) with a valid classification system for caregivers caring for an older person at home. *BMC Health Serv Res* 2018;18:229.
- Carduff E, Finucane A, Kendall M, *et al*. Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Fam Pract* 2014;15:48.
- Höppner C, Schneemilch M, Lichte T. Pflegende Angehörige und Ihre Belastungen in Hausarztpraxen Identifizieren – Hindernisse und Empfehlungen. *Zeitschrift Für Allgemeinmedizin* 2015;91:310–4.
- Broxson J, Feliciano L. Understanding the impacts of caregiver stress. *Prof Case Manag* 2020;25:213–9.
- Adelman RD, Tmanova LL, Delgado D, *et al*. Caregiver burden: a clinical review. *JAMA* 2014;311:1052–60.
- Parmar J, Anderson S, Dobbs B, *et al*. Neglected needs of family caregivers during the COVID-19 pandemic and what they need now: a qualitative study. *Diseases* 2021;9:70.
- Jarvis A, Worth A. The development of a screening tool to identify carers in a general practice by a large-scale mailed survey: the experience in one Scottish general practice. *J Clin Nurs* 2005;14:363–72.
- Wangler J, Jansky M. Prerequisites for providing effective support to family caregivers within the primary care setting - results of a study series in Germany. *BMC Fam Pract* 2021;22:252.

- 15 Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20:649–55.
- 16 Bédard M, Molloy DW, Squire L, *et al.* The Zarit burden interview: a new short version and screening version. *Gerontologist* 2001;41:652–7.
- 17 Hébert R, Bravo G, Prévile M. Validity and reference values of the Zarit burden interview for assessing informal caregivers of community-dwelling older persons with dementia. *Can J Aging* 2000;19:494–507.
- 18 Graessel E, Berth H, Lichte T, *et al.* Subjective caregiver burden: validity of the 10-item short version of the burden scale for family caregivers BSFC-s. *BMC Geriatr* 2014;14:23.
- 19 Mosquera I, Vergara I, Larrañaga I, *et al.* Measuring the impact of informal elderly caregiving: a systematic review of tools. *Qual Life Res* 2016;25:1059–92.
- 20 Marx Y, Frese T, Bauer A. Pflegende Angehörige in der Hausärztlichen Praxis – Hausärztliche Sichtweisen und Lösungsansätze. *Z Gerontol Geriatr* 2023;56:23–8.
- 21 Gräbel E. *Häusliche Pflege-Skala HPS: Zur Erfassung der subjektiven Belastung bei betreuenden oder pflegenden Personen*. Ebersberg: Vless, 2002.
- 22 The Joanna Briggs Institute. Joanna Briggs Institute Reviewers' Manual: 2015 edition / Supplement 2015, Available: <https://nursing.isuhsc.edu/JBI/docs/ReviewersManuals/Scoping-.pdf> [Accessed 11 Feb 2022].
- 23 Tricco AC, Lillie E, Zarin W, *et al.* PRISMA extension for scoping reviews (PRISMA-SCR): checklist and explanation. *Ann Intern Med* 2018;169:467–73.
- 24 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.
- 25 Bussiek P-BV, De Poli C, Bevan G. A Scoping review protocol to map the evidence on interventions to prevent overweight and obesity in children. *BMJ Open* 2018;8:e019311.