The challenge of identifying family carers in general practice at an early stage and measuring their burden: A scoping review of possible tools and their actual use

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ABSTRACT

Informal care, provided unpaid by family members or friends is a crucial source for providing care at home due to chronic illnesses, disability, or long-lasting health issues. An increasing burden on informal carers largely determines the already proven negative mental and physical health effects. General practitioners are usually responsible for recognizing the effects of persistent burdens on informal carers at an early stage to maintain a functional caring relationship by providing individual support. A scoping review was conducted in four databases (PubMed, LIVIVO, Cochrane Library, and Cumulative Index to Nursing and Allied Health Literature [CINAHL]) until July 31, 2023, to identify studies describing the actual use of tools to identify informal care and measure the burden due to informal care. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines were followed to select studies. A total of 5.686 references were identified, and 59 potentially eligible articles were assessed for inclusion, resulting in the inclusion of five studies published between 2009 and 2019. Instruments were primarily used to measure burden after an intervention; only one study focused on instruments to identify carers in general practice. This review highlights the need for a tool to identify informal carers in general practice, but it is important to consider practice-specific processes and settings. Future research should take a proactive approach to testing, modifying, and implementing an assessment and optimizing framework conditions. A follow-up project should be initiated to evaluate the effectiveness of an adapted identification tool on the burden and health of family carers.

Keywords: Burden, caring relatives, general practice, informal care

Introduction

The number of people in Germany requiring (long-time) care at home due to chronic illnesses, disability, or long-lasting health issues will increase by 37% by 2055. It is expected to rise from approximately 5.0 million at the end of 2021 to around 5.6 million in 2035 and 6.8 million in 2055.[1,2]

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Informal care is typically provided unpaid outside of a professional or formal framework by family members or friends.[1] These are crucial resources for caregiving.[3,4] The number of informal caregivers who reported spending at least one hour per day providing care was increasing from 4.1 million in 2019 to 5.7 million in 2021.[5]

Family carers often neglect their own health and suffer from exhaustion, particularly due to persistent psychosocial stress. An increasing burden on informal carers largely determines the already proven negative mental and physical health effects,

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such as anxiety or depressive symptoms, higher mortality risk, caregiving style, and abusive behavior.[6-11]

Although numerous interventions are available to address caregiver burden and improve caregiving outcomes, a critical issue that remains is the identification of these (over-) burdened caregivers.[12–14] However, support can only be provided if the carer is primarily identified as such. It is crucial to take a preventative approach before carers become overburdened. Very few are identified at an early stage of caring because they rarely identify themselves as such and ask for support.[15–17] As a result, they remain largely unsupported, which increases the risk for secondary physical and psychological morbidity and leads to several negative health consequences. In addition, caregiving frequently results in financial burdens and increased costs for both the family and the healthcare system.[11,15,18,19]

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 still insufficient.[16,20] Recent studies by Wangler in 2021 and 2022 show that 77% of general practitioners (GPs) consider themselves well-suited as the primary point of contact for family carers. This also applies to family carers of people who need palliative care.[21,22] In Germany, people with statutory health insurance have a legal right to specialized palliative home care, usually provided by GPs with additional qualifications. Thus, the GP often remains involved in the patient's treatment and supports patients with palliative care needs and their relatives.[23] However, the need to be proactively approached by the GP at an early stage of care is often not fulfilled.[21,22] Interviews Wangler (2019) conducted with 37 caregivers also stated that they initially felt uncertain about whether their needs and problems should be a matter for GP support.[24] This matches the outcomes of other studies, which showed that early and systematic identification of family carers remains challenging in the daily general practice setting.[15,21,22,24]

Several standardized and validated instruments for the identification and assessment of care-related burden exist, for example, the Zarit Burden Interview (ZBI) or the Burden Scale for Family Caregivers (BSFC).[25–30] Although reliability and validity have also been demonstrated, these scales are barely used as screening instruments in general practice.[31,32]

We conducted a scoping review to gain a better understanding of whether and how existing instruments or assessments to identify caring relatives and measure their burden are used in general practice.

Materials and Methods

A protocol for this review was registered on the Open Science Framework (OSF) (https://osf.io/9ce2k). This scoping review was guided by the Joanna Briggs Institute (JBI) approach and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist.[33,34]

The main objective is to identify tools used to assess and identify caregiver burden at an early stage of caregiving in general practice. The secondary objective is to describe factors and characteristics of tools or assessments that are associated with (systematic) use and successful implementation in general practice. Additionally, it will identify barriers that impede implementation.

Information sources and databases

We used an iterative search strategy involving the search for data in four electronic databases (PubMed, LIVIVO, the Cochrane Library, and Cumulative Index to Nursing and Allied Health Literature [CINAHL]) from June up to July 2023 and the reference lists of key studies to identify any studies eligible for inclusion.

Search strategy

A preliminary search was conducted in PubMed using database-specific Boolean operators based on the inclusion and exclusion criteria, using the terms 'general practice' and 'carer' and 'identification' (and their synonyms). In the second step, we developed a search strategy for PubMed using the preliminary search terms, supplemented by additional terms found in the preliminary search, such as specific tools related to family carers [Table 1]. For study protocols describing eligible studies, publications were searched on the basis of the registration numbers. The search strategy for the other databases was adapted accordingly, with the assistance of a librarian. For the database organization of the search results, we used the reference management tool Citavi.

Eligibility criteria

Studies were included if they met the criteria listed in detail in Table 2. Study protocols for proposed or ongoing studies that have not yet completed participant recruitment were included when the study protocol was deemed highly relevant for the review. In addition, some studies conducted in the context of palliative care were also included.

Data extraction

Two reviewers independently screened titles and abstracts and potentially eligible full-text articles and discussed different judgement. The first reviewer charted data from all included studies, and the second reviewer checked the extraction.

Results

A total of 5.686 references were identified, 468 were screened, and 59 potentially eligible articles that at least addressed the use of assessments or instruments for informal carers were read [Figure 1]. Five studies, published between 2009 and 2019, were included in the scoping review (Fortinsky, 2009; Hermann, 2012; Krug, 2016; Krug, 2017; Zwingmann, 2019).[35–39] As one

Table 1: Search strategy for PubMed database including relevant search terms covering family carer, general practice, instruments to measure, or to identify and burden

Query	Search terms
#1	("family carer"[All Fields] OR "family caregiver"[All Fields] OR "informal caregiver"[All Fields] OR "spouse caregiver"[All Fields]) AND (english[Filter] OR french[Filter] OR german[Filter])
#2	("family practice"[All Fields] OR (((("general practitioners"[MeSH Terms] OR ("general"[All Fields] AND "practitioners"[All Fields]) OR "general practitioners"[All Fields] OR ("general"[All Fields] AND "practitioner"[All Fields]) OR "general practitioner"[All Fields]) AND "or"[All Fields]) AND ("physicians, family"[MeSH Terms] OR ("physicians"[All Fields] AND "family"[All Fields]) OR "family physicians"[All Fields] OR ("family"[All Fields] AND "physician"[All Fields]) OR "family physician"[All Fields]))) AND (english[Filter] OR french[Filter] OR german[Filter])
#3	("instrument"[All Fields] OR "instrument s"[All Fields] OR "instrumentation"[MeSH Subheading] OR "instrumentation"[All Fields] OR "instruments"[All Fields] OR "instrumented"[All Fields] OR "instrumenting"[All Fields] OR ("diagnosis"[MeSH Subheading] OR "diagnosis"[All Fields] OR "screening"[All Fields] OR "mass screening"[MeSH Terms] OR ("mass"[All Fields] AND "screening"[All Fields]) OR "mass screening"[All Fields] OR "early detection of cancer"[MeSH Terms] OR ("early"[All Fields] AND "detection"[All Fields] AND "cancer"[All Fields]) OR "early detection of cancer"[All Fields] OR "screen"[All Fields] OR "screenings"[All Fields] OR "screened"[All Fields] OR "screens"[All Fields]) OR ("assess"[All Fields] OR "assessed"[All Fields] OR "assessement"[All Fields] OR "assesses"[All Fields] OR "assessing"[All Fields] OR "assessment"[All Fields] OR "assessment s"[All Fields] OR "assessments"[All Fields])) AND (english[Filter] OR french[Filter] OR german[Filter])
#4	("burden"[All Fields] OR "burdened"[All Fields] OR "burdening"[All Fields] OR "burdens"[All Fields] OR "care burden"[All Fields] OR "caregiver burnout"[All Fields] OR "caregiver exhaustion"[All Fields]) AND (english[Filter] OR french[Filter] OR german[Filter])
#5	("identifiable"[All Fields] OR "identifiably"[All Fields] OR "identifie"[All Fields] OR "identified"[All Fields] OR "identifier"[All Fields] OR "identifiers"[All Fields] OR "identifies"[All Fields] OR "identify"[All Fields] OR "identifying"[All Fields] OR ("measurability"[All Fields] OR "measurable"[All Fields] OR "measurably"[All Fields] OR "measure s"[All Fields] OR "measureable"[All Fields] OR "measured"[All Fields] OR "measurement"[All Fields] OR "measurement s"[All Fields] OR "measurements"[All Fields] OR "measurer"[All Fields] OR "measurers"[All Fields] OR "measuring"[All Fields] OR "measurings"[All Fields] OR "measurment"[All Fields] OR "measurments"[All Fields] OR "weights and measures"[MeSH Terms] OR ("weights"[All Fields] AND "measures"[All Fields]) OR "weights and measures"[All Fields] OR "measure"[All Fields] OR "measures"[All Fields])) AND (english[Filter] OR french[Filter] OR german[Filter])
#6	("Zarit Burden Inventory"[All Fields] OR "Caregiver Strain Index"[All Fields] OR "Caregiver reaction Assessment"[All Fields] OR (("caregiver s"[All Fields] OR "caregivers"[MeSH Terms] OR "caregivers"[All Fields] OR "caregiver"[All Fields] OR "caregiving"[All Fields]) AND ("demand"[All Fields] OR "demanded"[All Fields] OR "demanding"[All Fields] OR "demands"[All Fields]) AND ("scale s"[All Fields] OR "scaled"[All Fields] OR "scaling"[All Fields] OR "scalings"[All Fields] OR "weights and measures"[MeSH Terms] OR ("weights"[All Fields] AND "measures"[All Fields]) OR "weights and measures"[All Fields] OR "scale"[All Fields] OR "scales"[All Fields])) OR (("appraisal"[All Fields] OR "appraisals"[All Fields] OR "appraise"[All Fields] OR "appraised"[All Fields] OR "appraiser"[All Fields] OR "appraisers"[All Fields] OR "appraises"[All Fields] OR "appraising"[All Fields]) AND ("caregiver s"[All Fields] OR "caregivers"[MeSH Terms] OR "caregivers"[All Fields] OR "caregiver"[All Fields] OR "caregiving"[All Fields]) AND ("scale s"[All Fields] OR "scaled"[All Fields] OR "scaling"[All Fields] OR "scalings"[All Fields] OR "weights and measures"[MeSH Terms] OR ("weights"[All Fields] AND "measures"[All Fields]) OR "weights and measures"[All Fields] OR "scale"[All Fields] OR "scales"[All Fields])) OR "Burden Scale for Family Caregivers"[All Fields]) AND (english[Filter] OR french[Filter] OR german[Filter])
#7	S1 AND S2 AND S3 AND S4
#8	S1 AND S2 AND S4 AND S5
#9	S1 AND S2 AND S3 AND S4 AND S6

study protocol exactly met the inclusion criteria, it was included and a further publication was identified for this project through a targeted manual search.[36,38]

Overview of included studies

Three studies were randomized intervention studies (Fortinsky, 2009; Krug, 2017; Zwingmann, 2019) and one was an observational cohort study to identify correlations between changes in patients' quality of life and the burden of family carers (Krug, 2016).[35,37–39] Furthermore, one study protocol for an implementation study to develop a best-practice model for supporting family carers was included (Hermann 2012).[36] The studies included and the results in relation to the burden assessed are shown in Table 3.

Hermann (2012) was the only study to focus on the identification of family carers.[36] It was framed as an exploratory study for a subsequent implementation study (PalliPA), with a focus on the

feasibility and optimization of instruments that can be used in general practice to identify and measure burden. The first phase (completed at the time of publication) involved asking general practice teams about their approach to dealing with family carers. The second phase involved a participatory action research approach aimed at improving the identification of burdens. In a subsequent study of the PalliPA project, the burden was assessed after the intervention using the BSFC.[38]

Three intervention studies assessed the effectiveness of an intervention for patients or family caregivers by measuring their burden with similar objectives.[35,38,39] Participating GPs identified family carers based on specific diagnoses (associated with care needs) or directly through the patient receiving care, without the use of a special instrument to identify informal carers. Fortinsky (2009) aimed to evaluate the effectiveness of an individualized dementia counseling intervention for carers.[35] Randomization on the GP practice side was chosen.

	Inclusion	Exclusion
Population	Adult patients in general practices with burden caused by informal care of elder or chronically ill patients	Patients with known disease-specific health problems similar
Concept	Any kind of validated instrument (e.g., questionnaire and checklist) 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
Types of studies	Quantitative studies (e.g., cross-sectional studies, cohort studies, and case-control studies) Qualitative studies (interviews, focus groups, observations, and document studies) Mixed-method studies	Author replies/comments
Language, timeframe	German English French No timeframe	All other languages

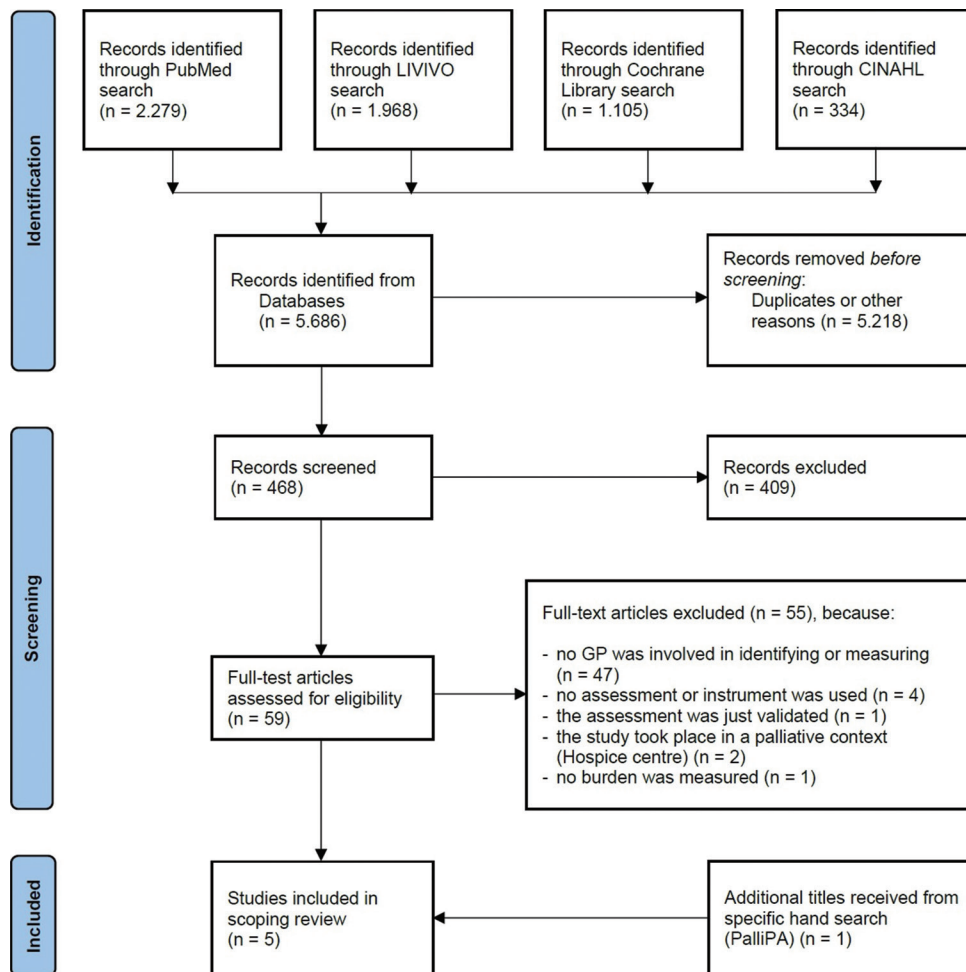<div align="center">Table 2: Inclusion and exclusion criteria for eligible studies</div>

Figure 1: PRISMA 2020 flow chart for study selection

Krug (2017) also reports on the results of the pilot project "Improvement of palliative care at home by supporting family caregivers" (PalliPA).[38] The study developed and tested measures to support family carers. Interviews were conducted with carers after the intervention, as the study also focused on the support and relief provided to family carers by the GP

practice. The burden perceived by the family carers was assessed using the BSFC. Zwingmann (2019) collected baseline data from family caregivers and patients with dementia (PwD) as a part of a GP-based, cluster-randomized intervention study. They used a comprehensive, standardized, computer-based needs assessment to investigate the association between family

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Table 3: Overview of included studies and key findings

Study	Origin and geographic context	Study type/aim of study	Instrument/tool used	Participants	Key findings concerning assessments and GP	Results of caregiver burden measures	Role of GP	
							Identifying family carer through	Measuring burden
Fortinsky 2009[35]*	US, the geographic setting included the greater Hartford, Connecticut metropolitan area and smaller cities	Intervention (individualized dementia care consultation for family caregivers)	22-item Revised Caregiver Burden Scale, ZBI[40]	84 caregivers	Sharing dementia care plans between physicians and non-medical consultants was successful, but only one quarter used them. The lack of initiative and change management behavior among physicians may be due to the increased complexity of care. Physicians face uncertainty	Results revealed no statistically significant treatment group-time interaction effects on burden (P 0.73)	Based on the electronic record billing systems at primary care practices, lists of patients with, for example, dementia were generated, and then verified by GPs. Primary contacts (as possible informal carer) were identified and contacted.	X
Hermann 2012[36]†	DE, GPs with an additional qualification in palliative medicine from the federal state of Baden-Wuerttemberg	Study protocol, exploratory trial for a subsequent implementation study, a participatory action research approach aim to improve identification and response to when support is necessary for family caregivers	The German version of the Burden Scale for Family Caregivers (BSFC)	At least 40 dyads (patient+caregiver)	General practitioners (GPs) are considered to be well-suited to meet the support and counseling needs of family caregivers. No studies have been found that examine the guideline in practice. The participatory action research approach allows GPTs to actively participate in the development of the implementation. Smaller changes have a greater chance of success than attempting to address all problems at once	No results are available yet	Each GP team develops its own individual strategy for identifying and relieving burdened caregivers. Patients with an incurable and life-threatening disease and their main family carer are then identified and included in the trial.	?
Krug 2016[37]†	DE, GPs in south-western Germany and their patients (Federal State of Baden-Wuerttemberg)	Prospective observational cohort study	Burden Scale for Family Caregivers (BSFC, short form-10 items)	100 dyads (patients with cancer and their carer)	The results confirm the professional need for GPs to regularly assess both patient needs and carer burden to enable early intervention. Regular assessment of carer burden by GP teams involved in the home care of palliative patients can be recommended.	Patients' dyspnea, feelings of depression, and anxiety affected the perceived burden on carers, but these are manageable symptoms.	Participating GP informed patients in a palliative situation with a diagnosis of advanced cancer and their caregiver	Participants received monthly BSFC-s from GPs, GPs were not informed of individual responses
Zwingmann 2019[39]*	DE, GPs in five municipalities of Mecklenburg-Western Pomerania	General practitioner (GP)-based, cluster-randomized intervention trial	Berlin inventory of caregivers' burden with dementia patients (BICS-D)[41]	317 dyads (226 on the intervention group, 91 in the control group)	The results indicate that conducting a comprehensive needs assessment, which includes domains such as the caregiving role, caregiver burden, as well as psychological and physiological health, is necessary to provide efficient support for family dementia caregivers. The development of assessments, prevention, and intervention programs depends on understanding and classifying the sources of burden, specifically the	Univariate analyses showed that a higher number of caregivers' unmet need was significantly associated with lower levels of mental health ($P<0.001$) of caregivers and high levels of: objective burden due to caring ($P<0.001$), subjective burden due to behavior change ($P<0.001$) subjective burden due to perceived conflicts between needs and responsibilities to care ($P<0.001$)	GPs systematically screened patients for dementia using the DemTect screening tool. Patients who screened positive (DemTect <9) and agreed to participate also provided contact to a caregiver.	Assessed by dementia-specific qualified study nurses

Table 3: Contd...

Study	Origin and geographic context	Study type/aim of study	Instrument/ tool used	Participants	Key findings concerning assessments and GP	Results of caregiver burden measures	Role of GP	
							Identifying family carer through	Measuring burden
						subjective burden due to role conflicts (*P*<0.001) somatization (*P*<0.001) depression (*P*<0.001) anxiety (*P*<0.001)		dimensions of caregivers' burden, and their consequences on health outcomes.
+ Publication identified through targeted hand search								
Krug 2017[38]†	DE, not specified, subsequent study of PalliPA Project[36]	intervention	Burden Scale for Family Caregivers (BSFC, long-form – 28 items)	27 caregiver	Results underline the importance of family practices recognizing caregivers as part of the care team to allow early and continuous support and thereby ensure care of palliative patients at home. Interventions initiated by GP practices and aimed at family caregivers can be successful if they can be easily integrated into everyday practice and the GPs are motivated.[42] When supporting relatives, the personal perception and commitment of each individual is very important, both for the GP and their team. Proactivity is of particular relevance in GP practices.[17]	Of the 27 relatives who participated, 26 relatives at baseline, 15 relatives after 6 months, and 9 relatives had completed the BSFC after 12 months. The burden decreased slightly.	Interventions were developed to help practice teams identify and alleviate the burden on relatives. Each GP practice established an internal register to identify patients receiving palliative care and their relatives.	Burden was assessed using BSFC at baseline, after 6 months and 12 months.

*Caregivers of PwD, †Palliative context

caregiver burden and health-related outcomes with unmet family caregiver needs.[39]

To examine the impact of quality of life in palliative care on the burden of family carers of terminally ill patients, the prospective observational cohort study (Krug, 2016) collected data from palliative patients and their family carers who were receiving care at home at the end of life by a GP also participating in the study.[37]

Population

The studies involved carers of PwD (Fortinsky, 2009; Zwingmann, 2019) or of patients in a palliative situation with a life-threatening disease, such as cancer (Krug, 2016; Krug, 2017; Hermann, 2012).[35–39] Participating GPs identified these carers in various ways: They used electronic record billing systems at primary care practices to identify primary contacts as potential carers.[35] They also conducted systematic screening for specific diagnoses associated with care needs (e.g. DemTect test).[39] In the context of palliative care, carers are identified and contacted directly through the patient due to the known presence of a life-threatening illness such as cancer and the resulting care situation.[36–38]

Carers were typically identified and recruited after the specific diagnosis was known and caring was already underway (Fortinsky, 2009; Hermann, 2012; Krug, 2016; Krug, 2017).[35–38] In Zwingman 2019, GPs systematically screened patients for dementia. A total of 317 patients tested positive (DemTect score <9). According to the medical records of participating practices, over 53% received their official diagnosis on the day of the screening, so their carers were identified at the beginning of their care activity. This study involved the largest number of 317 dyads (patients + carer).[39] The other studies involved 100 or fewer dyads.[35–38]

Concept: Included instruments and tools

Three instruments were used exclusively for measuring burden in the studies included, but not for identifying caring relatives and their burden [Table 4].

The ZBI, used by Fortinsky (2009) and originally developed to assess the burden among caregivers of PwD is one of the most widely used instruments to identify and measure the burden due to informal caregiving.[25,27,35,43,44,59] Three studies (Hermann, 2012; Krug, 2016; Krug, 2017) used the BSFC to measure the burden due to informal care.[28,30,47,60,61] Zwingmann 2019 used the Berlin Inventory of Caregiver Stress – Dementia" (BICS-D), a theory-driven, multidimensional assessment that was developed as part of the Longitudinal Dementia Caregiver Stress Study (LEANDER).[45,46,48,49]

Discussion of Results

Identification of family carers by GPs usually occurs through the patient receiving care, without the use of a special assessment

Table 4: Characteristics of included instruments		
	Burden Scale for Family Caregiver (BSFC)	**Zarit Burden Interview (ZBI)**	**Berlin Inventory of Caregiver Stress – Dementia (BICS-D)**
Version used	Long (28 items) and short version (10 items)	Long version (22 items)	Long version (121 items, 25 subscales), Practice version (33 items, 7 subscales)
Short forms available, for example	Short version (BSFC-s, 10 items)[28]	Several (validated) versions with a range of items from one to 18 [25,27,43,44]	BICS-D-PV, Practice version (33 items)[45,46]
Developed to	Intended to measure the burden and stress that arises from the caregiving situation[31,47]	Evaluate the subjective burden of family caregivers of PwD	Measure the objective and subjective burden resulting from caring for PwD[45,46,48,49]
Scale	Four-point Likert type scale (0=strongly disagree, 1=disagree, 2=agree, 3=strongly agree)	Five-point Likert type scale (0=never, 1=seldom, 2=sometimes, 3=quite often, or 4=almost always).	Questions on the scales ask to what extent the dementia patient needs support in these domains (five-point rating scales: "always," "mostly," "sometimes," "hardly ever," and "not at all")
use of the instrument	BSFC assesses statements related to the type of support provided by family caregivers. The questionnaire is appropriate for independent use by family caregivers. If used in paper format, a template for calculating the total score makes it easier to determine the total burden. The total load can be calculated automatically using a digitized version.	Family caregivers are provided with concise instructions to answer several questions regarding the impact of the illness of the patient they are caring for on their own life. For each item, they are required to indicate the frequency of their feelings The assessment is based on the addition of the numerical values assigned to each answer. Higher scores indicate a greater level of stress.	To conduct a risk assessment, it is necessary to use the questionnaire at least once To assess the effectiveness of your work, the instrument must be used twice at predetermined intervals Detailed instructions guarantee that older caregivers are able to respond appropriately to the questions[45] Interviewing person should possess experience in counseling or working with relatives to further support or instructions.
Target group(s): Caring relatives of (validated)	Patients with dementia (PwD)[47] Patients with chronic diseases and the need for chronic care[31] Patients with amyotrophic lateral sclerosis (ALS)[50]	PwD[51] Patients with schizophrenia[52] Older adults[53] Oncology patients[44]	Practice version (PV) has the potential to be used in cross-indication studies on home care for adults. Reliable and has factor validity also for informal caregivers of non-dementia patients, concerning construct validity further evidence is needed[45,46] Can also record specific intervention effects[46]
Pro and contra	Pro Easy to understand, can be completed independently by caring relatives Scale is validated using the increasing risk for psychosomatic symptoms in the case of increasing subjective burden[54] Contra Stressors are assessed in a one-dimensional manner, which may prevent the detection of specific effects of an intervention[46,55]	Pro Psychometric properties have been demonstrated in numerous studies Easy to assess[56] Contra Less/unidimensional structure appears inadequate for distinguishing between various caregiver sub-groups[46] Appears to lack sensitivity towards change→unsuitable for intervention studies[57]	Pro Sensitive to changes[58] Multidimensionality allows to target interventions and to measure intervention effects[48] Contra Scope originally pertains to the situation of family caregivers of PwD
Estimated time required to obtain information and complete the form	5–10 minutes	25 minutes	45-60 minutes

or instrument to identify informal carers. Thus, the three instruments identified in this scoping review were exclusively used to assess the burden due to informal care.

Implementation status of tools

No studies have been conducted on the actual use and implementation of instruments to identify informal carers in general practice. The BSFC is highly recommended for the standardized assessment in the guideline "Caregiving Relatives for Adults," so an appropriate level of awareness and implementation could be assumed.[61] However, a previous qualitative study

focusing on GPs individual perspectives and approaches for identifying caregiving relatives, although non-representative, indicates contrasting trends: although the interviewed twelve GPs feel fully responsible for the care of family caregivers and attribute an essential role to them, the majority was unaware of the guideline, and the BSFC was not used in their practices.[32]

Similar to Schneemilch (2018), these statements regarding the guideline allow conclusions to be drawn about potential improvements in guideline implementation.[62] Considering the results of other studies on guideline acceptance and use

in GP practice, it cannot be assumed that there is a general rejection of guidelines in principle.[63,64] Guidelines with primarily recommendations on drugs are more widely accepted and used than those with more communicative content. The implementation and use of the latter in practice depend on the time and structural possibilities of the GP.[65] The guideline "Caregiving Relatives for Adults" mainly contains recommendations that require GPs to have good communication skills, to allocate sufficient time, and proactive engagement on the patient's side. This may lead to implementation challenges.[24,63,65] Tian *et al.* (2023)[66] suggest involving primary care physicians in the guideline development process as an important solution for better implementation.

Practitioner ambivalence

Previous studies have shown that GPs are aware of the significance of family carers in the care process and the necessity for early identification. However, assessment is not explicitly prioritized due to time constraints in the practice routine, a lack of financial incentives, and undefined consequences.[32] The ambivalence is primarily due to the perceived lack of support for carers after completing a separate assessment.[32,67] Current research has confirmed that GPs are also often hesitant to discuss emotional and relational aspects of caring, as well as associated support needs. These most stressful aspects can significantly contribute to the breakdown of caring relationships and admissions to nursing and residential care homes.[67]

Factors affecting successful implementation

Implementation studies in general practices have demonstrated that interventions and assessments are better accepted and most effective when they can be easily integrated into existing procedures.[36,42] It is important that GPs can observe changes, are committed to the implementation, receive adequate support, and that the implementation is evaluated. That is why this participatory action research approach allowed GPs to actively participate in developing and implementing interventions. They utilized existing structures and procedures, optimizing them with the support of a research team. GPs can quickly and flexibly adapt to the implementation of new procedures, which can increase their motivation to adapt them to their practice routine.[36,42,68] When introducing a new tool in general practice, it is also important to assess the expectations of the staff, the perceived need for the assessment, and its potential compatibility with existing routines in advance.[69]

For the early identification of caregivers and the initiation of adequate support, it would be important that appropriate tools are available for use in routine general practice. Short screening scales are the most suitable option, considering time and personal resources in general practice. Based on the ZBI, Liew *et al.* (2019)[70] developed a three-item screening scale (ZBI-s) for assessing caregiver burden in dementia caregiving. They demonstrated that the shorter scale is as useful as the original 22-item ZBI, and even better than previous screening versions,

in identifying caregivers with significant burden who may benefit from further intervention. This validated version could serve as a basis for introducing an assessment in general practice that considers time-sensitive resources in the practice routine. All included instruments were developed for family carers of PwD, a long-term and slowly progressing functional disability. Other diseases such as incurable cancer can cause a rapid decline in health, which presents different challenges for family caregivers. Caregiving burden varies across different phases of care for all diseases.[36,71,72] When designing an instrument, it is important to consider not only time and personnel resources but also the patient structure and the expectations of the GP team. Hermann (2012) took a proactive approach to addressing these factors.[36] Previous studies have identified further obstacles to implementation that should be considered, such as the absence of a designated contact person for carers or the lack of cooperation with a care service.[73]

A first step in implementation could be the inclusion of the short BSFC or ZBI, modified and evaluated by the GP team, in an information brochure. The brochure should also contain notes on interpreting the results and specific recommendations for action. These brochures could be distributed to GP practices, etc., or made available on the internet.[31] This approach should be the focus of further research.

Alternatively, a procedure for identifying (pre-) frailty can be used, as described in the DEGAM guideline on basic geriatric assessment (currently under revision). The assessment begins with two signal questions to determine if a patient requires further evaluation. If necessary, a questionnaire (in this context: Manageable Geriatric Assessment [MAGIC]) is used to conduct the assessment, which may prompt additional investigations or interventions.[74] Although the effectiveness of their filter function has not yet been sufficiently proven based on current evidence, the guideline group recommends using two questions as signal questions for pre-selection in the waiting room due to their good applicability in everyday practice. These questions should relate to symptoms that are closely associated with (over-) burden due to caring activities and have been identified by GPs as indicative, such as depression, back pain, or headaches.[32] If the questions suggest that the caregiver is overwhelmed, an assessment (short) can be used as a reliable tool to evaluate the caregiver's burden and recommend interventions to alleviate it.

Furthermore, it is important to encourage family carers to acknowledge their role as such, identify themselves, and promptly discuss any issues with their GP.[17]

Conclusions

This review indicates an objectively measurable need for a tool to identify informal carers in general practice, but practice-specific processes, settings, and socio-cultural aspects must be taken into account. Future research should include a proactive approach to testing, modifying, and implementing an assessment and

optimizing framework conditions. A follow-up project should be initiated to use an adapted identification tool and evaluate its effectiveness on the burden and health of family carers and increase routine utilization.

Strengths and limitations

This review discusses the crucial public health issue of identifying caring relatives in general practice. The search strategy involved searching four electronic databases for peer-reviewed literature. It has been tailored and iteratively refined to retrieve as many relevant published studies as possible. The review may have been influenced by also using specific instrument names in the search terms for identification or measurement purposes. It is possible that instruments that were barely used and unknown to the authors were not included. Additionally, we searched the references of systematic reviews and did not find any additional studies, so we believe that we have not missed any relevant studies. It is also important to note that only publications in German, English, and French are included and the conclusions and practical implications primarily relate to the German healthcare system and the given framework conditions, which is a limitation.

List of Abbreviations

Abbreviation	Definition
ALS	Amyotrophic lateral sclerosis
BICS-D	Berlin Inventory of Caregiver Stress – Dementia
BSFC	Burden Scale for Family Caregivers
LEANDER	Longitudinal Dementia Caregiver Stress Study
MAGIC	Manageable Geriatric Assessment
OSF	Open Science Framework
PalliPA	Project: Improvement of palliative care at home by supporting family caregivers
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews
PV	Practice version
PwD	Patient(s) with dementia
ZBI	Zarit Burden Interview

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Conflicts of interest

There are no conflicts of interest.

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