Determinants of overburdening among informal carers: A systematic review

Nienke Lindt  
Wageningen University

Jantien van Berkel  
Wageningen University

Bob Mulder  
bob.mulder@wur.nl  
Wageningen University  
Corresponding Author  
ORCID: 0000-0003-0357-1370

DOI:  10.21203/rs.2.12116/v1

SUBJECT AREAS  
Geriatrics & Gerontology

KEYWORDS  
Informal care, stress, antecedents, Adapted Stress Model
Abstract

Background and Objective: The Dutch population is ageing, resulting in rising care demands and healthcare costs, which in turn led to a shift from formal to informal care. However, not only is the number of potential informal carers fastly decreasing, informal caregivers also experience higher caregiver burden. This literature review aimed at identifying the determinants of caregiver burden, to inform future interventions and foster informal care activities.

Research Design and Methods: A systematic review of peer-reviewed articles included in either PubMed, Scopus and/or PsychInfo has been conducted.

Results: 17 articles have been included. The most important predictors were the duration of caregiving and the dependency level of the patient, both in terms of physical dependency and mental dependency stemming from decreased cognitive capacity or behavioral problems. Some specific illnesses and role conflicts or captivity also increased burden, while social support lowered it. Being a female caregiver or having an adult-child relationship led to higher burden.

Discussion and Implications: Firstly, it is recommended that specific interventions are designed for carers most at risk and that they focus on increasing the patient’s physical and mental independency. Moreover, interventions need to be adapted to the illness trajectory of specific diseases and the adhering needs for social support of both the recipient and caregiver. Lastly, role expectations should be changed, leading to men being more involved. Future research could focus on determining causality, the concept of ‘time’ and the relevance of cultural expectations.
The Dutch population is ageing and the percentage of elderly will continue to rise in the upcoming years. Where the percentage of people aged 65 or higher was 17.8% among the Dutch population in 2015, it is estimated that in 2060 the elderly will account for 25.8%. In absolute figures, this means that roughly 4.8 million Dutch citizens will be aged 65 or higher in 2060 (1). Due to the aging population, the demand for care is also rising. It has been established that when people are getting older, they will suffer from more (chronic) illnesses, needing long-term care. Among the people aged 65 years or older, 70% suffers from a chronic disease. When zooming in on the population aged 75 years or older suffering from a chronic disease, 63% actually has two or more chronic illnesses (2). This results in the care volume increasing by 4% every year, leading to higher overall healthcare costs (3).

1.1 Informal care

In order to face these rising care demands and healthcare costs, the Dutch government is steering away from formal care and towards informal care. To ensure accessibility, affordability and the quality of care the Dutch government reformed the long-term care policies in 2015. Following from this Dutch Social Support Act, Dutch elderly are stimulated to stay at home longer instead of moving into nursing homes. In order to make this feasible, elderly will have to rely on their direct network of family and friends to ensure informal care (4). Combining the trend of an ageing society and policy reformations, the need for informal care will be increasing the upcoming years.

But how can informal care be defined? According to the SCP (Sociaal en Cultureel Planbureau) [Social Cultural Planning Agency] informal care is the following: ‘Informal care constitutes all aid to a person in need of care from someone in his or her direct environment. This also entails less intensive help, help towards members
of the household and help towards institution residents. Informal care goes further than so-called ‘regular help’. With ‘regular help’, the aid that may reasonably be expected towards members of the household is meant, for instance the care for children. Examples of informal care activities are emotional support, administrative help, guidance in arranging appointments, transport, domestic and personal care (5). The Dutch government stresses the fact that informal care is unpaid, resulting from social relations instead of profession, and entails the long-term care for sick family members or friends (6).

In 2016, more than a third of the Dutch population (36%) over 16 years old gave some type of informal care. Most informal carers are aged between 50 and 75 and take care of partners or parents (in law) (7). The biggest group of people in need of informal care are aged 75 and over (8).

Even though the need for informal carers is rising, a current report states that by 2040 the amount of potential informal carers per elderly person aged 75 or higher will be halved from 4 to 2 potential carers, resulting in informal care shortages especially in rural areas (7).

1.2 Caregiver burden

Next to the pressing future shortages in informal carers, it has been shown that almost one in 10 informal carers feels overloaded with the care demand. In absolute figures, this means roughly 380.000 informal carers feel heavily pressured. When zooming in on the people providing long-term and intensive informal care, one in four feels stressed out. Not only do they feel as if the care demand is never lifted from their shoulders, they struggle with the upkeep of their own household and feel overstrained (9).

This caregiver burden can be defined as ‘a multidimensional response to the
negative appraisal and perceived stress resulting from taking care of an ill individual’ (10). Overburdening threatens both the physical and psychological health of caregivers. It has been shown that overstrained caregivers use more healthcare services and prescribed medication than non-caregivers, indicating a decline in physical health (11). Moreover, stressed caregivers report more feelings of depression, perceived lack of coping mechanisms and concerns about their poor quality of life (12). Combining this burden with the decrease of potential informal carers, it becomes apparent that the caregiver burden needs to be alleviated, in order to cope with the rising informal care demand in the future.

1.3 Research objective

Research has already been done regarding the determinants of informal caregiver burden. For instance, a systematic review of Van der Lee, Bakker, Duivenvoorden and Dröes (13) led to several categories of both patient and caregiver determinants, such as the patient’s need for support, (cognitive) function disorders and the caregiver’s social functioning, self-efficacy and coping traits. Consequently, a lot of research has been done into possible interventions that are based on such determinants (14, 15). These interventions generally focus on both direct and indirect caregiver support, such as emotional support, advice on coping and respite services to reduce the amount of care provided by the caregiver (16). However, systematic reviews on such interventions show that the effects on caregiver burden are very small or even insignificant (17, 18). This provides the rationale for updating the overview of the determinants of caregiver burden. The current research consists of an in-depth literature review regarding the determinants of the perceived burden, which will help in creating more effective interventions and ensuring informal care in the future. Therefore, the following
research question is formulated: *what are the determinants of caregiver burden among informal carers?*

### 1.4 Hypotheses

The construct of ‘caregiver burden’ knows many different definitions due to its multidimensionality. According to George and Gwyther (19), it entails physical, psychological, emotional, financial and social stressors that individuals experience because of providing care. Depending on the scope of the research and included facets, the definition of caregiver burden differs per study (20).

Moreover, the distinction between objective and subjective burden adds to the complexity of the construct of ‘caregiver burden’. Montgomery, Gonyea and Hooyman (21) state that: *objective burden is defined as the extent of disruptions or changes in various aspects of the caregivers’ life and household. Subjective burden is defined as the caregivers’ attitudes toward or emotional reactions to the caregiving experience*’ (p. 21). Thus, objective burden entails overt aspects, such as time spend on caregiving, the nature and number of tasks, whereas subjective burden encompasses caregiver perceptions of the care demands and its consequences, such as negative mood states and anxiety.

Both the multidimensionality of, and the objective-subjective distinction within, caregiver burden are reflected by the Adapted Stress Model (ASM). The ASM describes the relationships between various categories of determinants that ultimately cause perceived caregiver burden (Fig. 1).

**[insert figure 1 here]**

The ASM is based on stress theories, notably the transactional model of stress and coping (22) and the stress process model (23), as well as role theory (24). Going from the left side of the model to the right, the ASM allows for the
formulation of specific hypotheses, including their rationale.

**H1: Direct effects of stressors on perceived caregiver burden.**

Whereas hypotheses 2, 3 and 4 describe indirect (i.e. mediated) effects of general stressors through role and intrapsychic stressors, it is hypothesized that each class of stressors in the ASM may also directly result in perceived caregiver burden.

**H2: General stressors result in an estimated number of hours spent on caregiving.**

The general stressors are the patient’s cognitive status, problematic behavior, dependency level, specific illness and care demands. Together, these five general stressors lead to the caregiver’s primary appraisal of the severity of the stressor (22), which translates into the estimated number of hours that need to be spent on caregiving.

**H3: The estimated number of caregiving hours leads to role conflict and role overload.**

Resulting of the estimated number of caregiving hours, caregivers may experience role conflict and role overload as role stressors. Role conflicts occur when the expectations of the various roles the caregiver fulfils become incompatible (24). Theoretically, this is in line with the secondary appraisal from the transactional model of stress and coping, which is the appraisal of one’s resources (e.g., time) to manage the stressor (22). In the case of informal care, the role of informal carer may lead to conflicts with the roles of being a parent or an employee.

Role overload happens when people lack sufficient resources and time to fulfil all obligations linked to their roles (25). For instance, when the number of caregiving hours increases, it may result in role overload when the caregiver feels he or she lacks hours in the day to complete all tasks associated with every role he or she occupies.
**H4: Role stressors may lead to intrapsychic stressors.**

Role conflict and overload may result in role captivity, the feeling of entrapment within the caregiving role and related experience of self loss (26). For instance, caregivers may give up activities related to other roles, such as quality time with their partner, in order to take care of their ill parent. It has been established that role captivity and loss of self lead to higher feelings of depression and burden (26, 27). In addition to this situational burden, role and intrapsychic stressors may negatively affect self-esteem and feelings of competence.

**H5: Coping strategies and social support moderate the relationships between stressors and perceived caregiver burden.**

Finally, the relationships between stressors and perceived caregiver burden may be moderated by coping strategies and perceived social support. Coping can be defined as the cognitive, emotional and behavioural efforts to manage the internal and environmental demands that challenge or exceed someone’s resources (22). According to Carver, Scheier and Weintraub (28) coping efforts can be divided into three different categories; namely problem-focused coping, emotional-focused coping and dysfunctional coping. Problem-focused coping entails strategies used to solve certain problems, such as thinking about the steps that need to be taken in order to solve the problem. When the caregiver tries to reduce or eliminate negative feelings connected to the role, such as the acceptance of reality, this can be considered a type of emotional-focused coping. Lastly, dysfunctional coping happens when people do not accept the problem at hand and try to ignore or even refuse reality, and this is positively associated with feelings of anxiety, depression and perceived burden (29, 30). In contrast, problem-focused coping does not appear to be related to caregiver burden (30, 31). Whether emotional-focused coping and
burden are related is not consistent in current literature. However, cases of informal care among palliative cancer patients or people suffering from dementia, show that emotional-focused coping leads to a decrease in perceived burden (31, 32). Perceived social support is the second moderator in the ASM. Informal caregivers receiving social support from own contacts or professionals in general experience less burden than others (33). According to Thompson, Futterman, Gallagher-Thompson, Rose and Lovett (34), social support that allows caregivers to engage in social interaction for fun and recreation is the most important in decreasing perceived burden. Other forms of social support are informational and emotional support, and tangible assistance. Respite care is a special type of social support where social interaction and tangible assistance are combined. Here the care tasks are temporarily lifted from the informal caregiver’s shoulders in order to alleviate burden. Moreover, respite care should free up time, so caregivers can perform other roles. However, results on the effectiveness of respite care on caregiver burden are heterogeneous (35).

Research Design & Methods

For this study, a systematic review has been conducted. Within this chapter the methodology is described, consisting of the database search strategy, inclusion criteria and selection process. The first author (NL) developed the search strategy and performed the first search, which initially resulted in 13 articles. The search strategy (databases, search terms and inclusion/exclusion criteria) was repeated independently by the second author (JvB). Differences were solved by discussion, resulting in the addition of 4 more articles.

3.1 Database search strategy
Three different databases have been used for the literature search, namely Medline, PsycINFO and Scopus. Medline and PsycINFO have been searched simultaneously via EBSCOhost. In order to achieve relevant search hits, a field code (namely IT) has been used in all databases. It has been decided to make sure the terms caregiver, carer or caregiving AND burden, stress, strain, burnout or overstrained were present in the title of the search hits. To narrow down the search results further, the articles had to be written in English. A detailed overview of the search strategy can be found in Table 1. Moreover, since the earlier stated research of Van der Lee et al. (13) searched up to December 2013 to determine factors leading to caregiver burden, it has been decided to search from 2013 onwards. Due to this date limit, articles not incorporated in their research were included in the current literature review. The preliminary multiple database search provided a total of 528 articles, after removing duplicates. The articles then were stored in an EndNote X8 database.

**insert table 1 here**

3.2 Inclusion criteria

In order to reach a final selection of articles, multiple inclusion criteria were established. Firstly, (i) caregiver burden needed to be a key concept in the study and had to (ii) include the multidimensionality of caregiver burden, corresponding with the theoretical framework of this research (i.e. include both objective burden measures (such as time spend on caregiving, the nature and number of tasks) and subjective burden measures (such as caregiver perceptions of the care demands and its consequences, such as negative mood states and anxiety)). In order to focus the literature review on the context of caregiving at home, (iii) studies with hospitalised patients (i.e. inpatients), were excluded. (iv) Moreover, the patients still needed to be alive during the research period in order to focus the research on
caregiver burden during caregiving (i.e. no retrospective orientation). Next, (v) only studies that examined associations between informal care and some measure of burden or stress were included and (vi) articles had to report empirical research with a minimum of 100 respondents to make sure statistical relationships and differences are relevant and representative for a whole population. Moreover, (vii) research had to be conducted in Western countries. Reason for this, are the presumable societal and cultural differences between Western and non-Western countries that might play a role in informal care. Lastly, the articles had to be (viii) published in a peer reviewed journal.

3.3 Selection process

As a first step of the selection process, the abstracts of the articles were screened on the established inclusion criteria. This resulted in a preliminary selection of 30 articles. Then, the full texts of this selection were critically analysed based on the same inclusion criteria. From this, another 13 articles were omitted, resulting in a final selection of 17 articles for the current literature review (Fig. 2). An overview of the included articles can be found in appendix I.

**insert figure 2 here**

Results

Of the 17 included studies, fourteen published cross-sectional studies, while three reported longitudinal studies. Thirteen studies measured caregiver burden via validated research instruments. Only one instrument was used in four different studies, namely the Zarit Burden Interview (ZBI). This specific instrument was used in every paper that reported about caregiver burden in dementia care. An exemption to this, was the article of Laporte Uribe (36) that used BIZA-D as an
alternative to ZBI. A descriptive table with all included studies can be found in Appendix 1. In this chapter the results regarding stressors, moderators, miscellaneous factors and background characteristics are discussed.

4.1 General stressors

The three longitudinal studies all found that the duration of caregiving and the patient’s functional status were the strongest determinants of burden (37–39). In every longitudinal study, caregiver burden increased non-linear over time since perceived burden increased at a steeper rate as time progressed. This shows that duration is an important factor. Guerriere et al. (37) argued that this might happen due to progression of the disease of the care recipient. However, it can also be hypothesised that duration has a more direct effect on caregiver burden, independent of disease progression; the burden becomes heavier the longer caring tasks are performed. This then could be explained via hypothesis 3, where duration is expected to increase role overload.

Moreover, these three longitudinal studies as well as six cross-sectional studies considered the patient’s functional status in terms of dependency level in activities of daily living (henceforth shortened to ADL) as one of the strongest predictors of perceived caregiver burden (36–44). This is consistent with the ASM, where ADL dependency is considered a general stressor. The influence of dependency level could be explained via an increase in both the intensity of caregiving and amount of caregiving tasks required, leading to higher burden (37, 40). Lethin et al. (38) linked ADL dependency in their longitudinal study specifically with increased need for supervision hours in the case of dementia care, providing support for hypothesis 2.

In contrast to the duration of caregiving, the role of hours spent on caregiving per
week or month showed mixed results. The cross-sectional research of De Almeida Mello et al. (41) and Blanthorn et al. (45) and the longitudinal studies of Lethin et al. (38) and Guerriere et al. (37) considered hours spent on caregiving a determinant of caregiver burden. However, the cross-sectional study of Riffin et al. (44) reported that time spent is no longer associated with caregiver burden after accounting for the number of caregiving tasks. According to them, the provision of additional responsibilities may be more taxing on the informal carer than the time demand. From this, it can at least be hypothesised that there are more indirect factors, such as the number of tasks, that influence caregiver burden and the perceived time demands.

Another factor that influenced informal caregiver burden is the specific illness of the patient. This is confirmed by four studies that claim that illnesses such as dementia, solid tumours, physical disabilities or the presence of comorbidities are positively associated with burden (39, 43–44, 46). This confirms the place of ‘specific illness’ as a general stressor in the ASM and supports hypothesis 1, i.e. general stressors (such as specific illness) have both indirect and direct effects on perceived burden.

Finally, the mental state of the care recipient, namely behaviour and cognitive capacity, appeared to be relevant. This matches with the ASM, where these factors are labelled as general stressors and again confirms the direct effects of behaviour and cognitive capacity on burden as formulated in hypothesis 1. Both the longitudinal studies of Ransmayr et al. (39) and Lethin et al. (38) and cross-sectional studies (36, 41, 45, 47–48) incorporated patient’s behavioural problems such as agitation and aggression in their research and this showed to be positively related to caregiver burden. These factors seem especially relevant in the context
of dementia care, where such behavioural problems occur frequently.
Next to behaviour, three articles, both longitudinal and cross-sectional, also reported about the cognitive capacity of care recipients (38, 41, 49). From the research in these articles it becomes apparent that the patient’s cognitive status indeed has predictive value for caregiver burden; reduced cognitive function of the recipient leads to higher burden.
In conclusion, all general stressors included in the ASM have direct effects on caregiver burden, supporting hypothesis 1. Studies on dependency level as a stressor provided indirect support for Hypothesis 2, in addition to one study that specifically confirmed that dependency level translated into an estimation of the needed supervision hours.

4.2 Role and intrapsychic stressors

Ransmayr et al. (39) found in their longitudinal study that burden also builds over time due to restrictions in time for other activities and psychological distress of the caregiver. This could be linked to role theory, entailing both role conflict, which most likely is the case when less time is available for other activities, and role captivity or role overload, referring to the psychological distress.
The relevance of role conflict is confirmed by three cross-sectional studies, that firstly showed the influence of ‘job-caregiving conflicts’, which are incorporated as one type of role conflicts in the ASM (41, 43, 50). Their research not only showed that informal carers who combine work and care experience the highest burden (50), a higher IADL dependency in combination with employment is also positively related (43). Secondly, the cross-sectional study of De Almeida Mello et al. (41) confirmed both the ‘job-caregiving conflict’ and revealed ‘family conflict’ to positively influence caregiver burden, which is also a type of role conflict.
Taken together, these studies support hypotheses 3 and 4; informal care may lead to both role conflict and role overload, and these, in turn, may result in additional intrapsychic stressors. Moreover, the cross-sectional studies provide support for hypothesis 1 since role conflict directly affects burden.

4.3 Social support as moderator

Five studies, both longitudinal and cross-sectional, included social support in their research (36–37, 43–44, 49). It was found that a higher quality of support, both formal and informal, for the caregiver is associated with lower burden, whereas unmet needs for health and social services contribute to caregiver burden (49). Moreover, cross-sectional research of Hsu et al. (43) refered to the importance of social support aimed at the patient, leading to lower caregiver burden. From this, it can be deducted that it is important to make sure both the caregiver and recipient feel well supported both by the direct environment and by available professionals. Surprisingly, the articles did not explain, both in theory or via empirical testing, the exact mechanisms that cause social support to affect caregiver burden. However, the fact that social support at least correlates negatively with burden partly supports hypothesis 5 about the moderating effect of social support on the stressor-burden relationship. No studies addressed the effects of specific coping strategies on care burden.

Next, the specific role of respite services showed some mixed results at first glance. Longitudinal research of Guerriere et al. (37) found that the number of hospice days of a patient were negatively related to caregiver burden; the more days a patient spent in a hospice instead of at home, the lower the burden for the informal caregiver. Hospices are often used as a type of social support or respite services, where patients are admitted during the day or for several days in the week to
alleviate care responsibilities for the carer. However, the cross-sectional research of Riffin et al. (44) showed a positive relationship between using respite services and burden. This seems like contradictory evidence, but it should be stated that causality cannot be determined from cross-sectional research. Therefore, it could be argued that a positive relationship is found due to progression of the disease, which indirectly influences the need for and use of respite services due to the intensity of caring. These potential effects of the general stressors on the moderators have not been hypothesised.

4.4 Miscellaneous factors

The cross-sectional research of De Almeida Mello et al. (41) was especially interesting for the current literature review, since they have based their empirical research on the same recommendations of Bastawrous (20) that have been used for the ASM in this review. They used the factors of Pearlin et al.’s stress process model (23) as input for their research, next to potential determinants from role theory. Additional factors that appeared relevant in their research, next to the already mentioned determinants, were depressive symptoms, previous admissions to nursing homes, risk of falls, cohabitation and an adult child relationship between the caregiver and care recipient. These all had a positive relationship with caregiver burden, which can be interpreted as support for hypothesis 4. Lethin et al. (38) and Juntunen et al. (49) confirmed that (risk of) depression correlates with caregiver burden, especially among men in the research of Juntunen et al. (49). However, whether cohabitation and the relationship between caregiver and patient are significant determinants for caregiver burden, is being disputed within the included articles.

In the cross-sectional and longitudinal studies of Braich et al. (40), Guerriere et al.
(37) and Hsu et al. (43), the relationship between caregiver and care recipient appeared irrelevant. In contrast, Riffin et al. (44) and Laporte Uribe et al. (36) found that an adult child relationship leads to higher burden in their cross-sectional study. These contradictory results could be explained due to the presence of different types of burden. Two cross-sectional studies identified different types of burden via exploratory factor analysis (50–51). According to them, caregivers experience different types of burden depending on the specific kinship role. This is in line with, for instance, the cross-sectional research of Juntunen et al. (49) where differences were found in the determinants of caregiver burden for spouses, daughters and mothers of the care recipient. Therefore, the relationship type between caregiver and recipient can be considered relevant and would most likely be a valuable addition to the ASM.

Lastly, the longitudinal research of Guerriere et al. (37) found living arrangements, such as cohabitation, to be insignificant. However, Ransmayr et al. (39) do state that the physical proximity of the patient correlates positively with caregiver burden in their longitudinal research. Here, results remain inconclusive and unambiguous conclusions on living distance cannot be drawn.

4.5 Background characteristics

Finally, some interesting background characteristics were researched in the selected articles. Seven out of the seventeen articles labelled being a female caregiver as correlating positively with caregiver burden. In other words, female caregivers experience more subjective burden than male caregivers. Whether the gender of the patient and age of the caregiver and patient are also relevant, cannot be concluded, since results were inconclusive. Next, the overall health, well-being and quality of life of the caregiver showed to be important. For instance, research of
Riffin et al. (44) stated that caregivers in poor health or with anxiety symptoms experience higher informal caregiver burden.

Discussion and Implications

Firstly, this chapter contains the conclusion of the current systematic review. Moreover, the findings are discussed in light of both academic and practical relevance. Next, the strengths and limitations are considered. Lastly, future research opportunities are considered.

5.1 Conclusion

The aim of this research was to establish the determinants of caregiver burden among informal carers. All of the determinants incorporated in the ASM were found to have direct effects on caregiver burden in the literature review, providing strong support for hypothesis 1. The most important predictors of caregiver burden were the duration of caregiving and the dependency level of the patient. The longer someone had to provide informal care or the more dependent the patient became, the higher the perceived burden. Besides physical dependency, the recipient’s mental state in terms of behavioural problems and cognitive capacity was also a determinant of dependency level, as these were positively related to caregiver burden. Some specific illnesses, such as dementia or solid tumours, also led to higher burden.

Even though duration of caregiving proved to be an important predictor of caregiver burden, the support for hypothesis 2 was more mixed, partly because time spent on caregiving appeared to be an ambiguous construct; studies either reported the total duration of caregiving, or the hours spent per week or month. Only one study found evidence that the stressor ‘dependency level’ resulted in an estimate of the number
of care hours to be spent. Even though both duration and time spent were positively related to caregiver burden, the exact reasons for these effects are not fully clarified. Duration of caregiving would be a valuable addition to the ASM. Potential explanations for the effects of duration of and time spent on caregiving were progression of the disease, role captivity or role conflicts, indirectly supporting hypothesis 3. In addition, the presence of role conflicts or role captivity also increased informal caregiver burden. However, the articles did not investigate the causal relationship between role stressors and intrapsychic stressors, so no definitive answer could be given regarding hypothesis 4. Social support seemed to lower the perceived burden due to its moderating role on the relationship between stressors and perceived burden. No studies reported about the effect of coping strategies on caregiver burden; therefore, hypothesis 5 is only partially supported. In terms of background characteristics, female caregivers experienced more stress over time. In addition, the different kinship roles led to different types of caregiver burden. Therefore, the relationship type between caregiver and care recipient should be added to the ASM. Lastly, it should be noted that much findings were discussed as covariates in the articles, but causal relationships could not be derived since the studies did not determine causality both theoretically or via empirical testing.

5.2 Academic relevance

When comparing the outcomes of the current literature review with the established determinants of caregiver burden in the systematic review of Van der Lee et al. (13), a few differences stand out. Van der Lee et al. (13) marked the patient’s behavioural problems to be one of the strongest determinants of caregiver burden (79%), whereas the level of patient’s self-care, which is similar to dependency level,
only contributed for 36% to caregiver burden. In the current literature review, dependency level appeared more important than behavioural problems for caregiver burden. The main explanation for this difference can be found in the fact that the review of Van der Lee et al. (13) focused on dementia care, where behavioural problems occur more frequently than with other diseases. This again confirms the importance of the specific illness as a general stressor of caregiver burden.

Moreover, Van der Lee et al. (13) also established the importance of social support, but only aimed at the caregiver. The current literature review also showed the importance of social support towards the patient.

5.3 Practical implications

Based on this literature review, recommendations can be made for future interventions. Firstly, it is important to focus on the specific carers most at risk of caregiver burden since research has shown that female informal caregivers, providing dementia care and child caregivers predict higher burden. Besides specific interventions for these groups, it appears that increased involvement of men in informal care provides an opportunity to relieve the burden of female caregivers. The current social norm holds that women take up more caring tasks than men; however, such role expectations threaten the sustainability of informal care in the light of rising care demands in the future.

Secondly, interventions could benefit from adaptation to the course of specific illnesses, as it appears that burden increases non-linear over time. For example, it could be determined at which moments during the illness trajectory interventions would be most needed to support caregivers. This can also involve interventions on different levels, such as interventions aimed at the individual where the focus could be on increasing the patient’s independency both mentally and physically, but also
aimed at the organisations involved in the caregiving trajectory.

5.4 Future research

There are some interesting future research opportunities indicated by this literature review, the outcomes of which could be used to optimize interventions aimed at relieving informal care burden. First and foremost, experimental designs are needed to determine the causality between determinants. Specifically, the effects of different types of respite care could be tested experimentally, as to their effectiveness in relieving care burden.

Moreover, this research domain would benefit from more longitudinal studies, enabling trend analyses regarding the trajectory of informal caregiver burden over time. Since the concept of ‘time’ cuts straight through both the primary and secondary stress appraisals, and contains both objective and subjective elements, it warrants further attention. For instance, it not only influences the appraisal of the stressful event of informal caring, but also the perceived hours available for other roles.

Lastly, during the selection process, a large proportion of research appeared to have been carried out in Asian countries, which have collectivistic cultures. For the current review, these studies have been excluded. It could be interesting to conduct a comparative study in the future between the Western and Asian world in order to determine the relevance of cultural expectations on informal caregiver burden.

5.5 Limitations and strengths

For this research some limitations should be noted. Firstly, most of the included articles of the systematic review consisted of cross-sectional research. Therefore, causality between the different concepts could not be determined properly. Due to
this, the actual process or framework (via indirect effects) cannot be validated. Moreover, the articles only consisted of research done in Western countries, which could have affected the generalisability of the outcomes of the research. However, overall this systematic review also knows certain strengths. In the vast array of articles available on the topic of informal caregiver burden, an efficient selection has been made with a clear search strategy. This strategy comprised of only selecting studies with larger samples (n>100), as those studies knew larger explanatory (statistical) power. Moreover, this literature review had a strong theoretical framework, already uncovering most of the determinants later found during the review. The empirical studies from the articles later on provided more insights into these determinants.

Declarations

Conflict of Interest. The authors declare that they have no conflict of interest.

Availability of data and material. All data generated or analysed during this study are included in this published article [and its supplementary information files].

Authors’ contributions. NL and BM set up the research protocol; NL and JB independently carried out the literature search and selection; all authors critically reviewed the manuscript, read and approved the final manuscript.

List of Abbreviations

ADL, activities of daily living

ASM, adapted stress model

SCP, Dutch social planning agency

ZBI, Zarit Burden Interview
Bibliography

1. CBS. Prognose bevolking: geslacht en leeftijd, 2019–2060 [Population Forecast: gender and age, 2019–2060] [Internet]. 2018 [cited December 18]. Available from: https://opendata.cbs.nl/statline/#/CBS/nl/dataset/84346NED/table?ts=1545996308401

2. Schumacher J. Cijfers: vergrijzing en toenemende zorg [Facts: ageing population and increasing care]. Zorg voor Beter 2017.

3. Van der Horst A, Van Erp F, De Jong J. Trends in gezondheid en zorg [Trends in Health and Care]. Den Haag: Centraal Planbureau; 2011.

4. Wet Maatschappelijke Ondersteuning [Dutch Social Support Act]. 2015. Available from: https://wetten.overheid.nl/BWBR0035362/2018-11-17.

5. De Klerk M, De Boer A, Plaisier I, Schyns P, Kooiker S. Informele hulp: wie doet er wat? [Informal Care: who does what?]. Den Haag: Sociaal en Cultureel Planbureau; 2015.

6. Rijksoverheid [Dutch National Government]. Wanneer ben ik mantelzorger? [When am I an informal carer?] Mantelzorg. 2018. Available from https://www.rijksoverheid.nl/onderwerpen/mantelzorg/vraag-en-antwoord/wanneer-ben-ik-mantelzorger

7. De Jong A, Kooiker S. Regionale ontwikkelingen in het aantal potentiële helpers van oudere ouderen tussen 1975 en 2040 [Regional developments in the number of potential helpers of older elderly between 1975 and 2040]. Den Haag: Uitgeverij PBL (Planbureau voor Leefomgeving); 2018.

8. Putnam L, Verbeek-Oudijk D, De Klerk M. Zorg en ondersteuning in Nederland: kerncijfers 2014. Ontvangen hulp bij het huishouden, persoonlijke verzorging,
verpleging en begeleiding [Care and support in the Netherlands: key figures 2014. Household assistance, personal care, nursing and counselling received]. Den Haag: SCP; 2016.

9. De Klerk M, De Boer A, Plaisier I, Schyns P. Voor elkaar? Stand van de informele hulp in 2016 [For each other? Status of informal care in 2016]. Den Haag: Sociaal en Cultureel Planbureau [Social and Cultural Planning Agency]; 2017.

10. Kim H, Chang M, Rose K, Kim S. Predictors of caregiver burden in caregivers of individuals with dementia. Journal of Advanced Nursing. 2012:846-55.

11. Serrano-Aguilar PG, Lopez-Bastida J, Yanes-Lopez V. Impact on health-related quality of life and perceived burden of informal caregivers of individuals with Alzheimer's disease. Neuro-epidemiology. 2006:136-42.

12. Molyneux GJ, McCarthy GM, McEniff S, Cryan M, Conroy RM. Prevalence and predictors of carer burden and depression in carers of patients referred to an old age psychiatric service. International Psychogeriatrics. 2008:1193-202.

13. Van der Lee J, Bakker TJ, Duivenvoorden HJ, Dröes RM. Multivariate models of subjective caregiver burden in dementia: a systematic review. Ageing research reviews. 2014:76-93.

14. Boezeman EJ, Nieuwenhuijsen K, Sluiter JK. An intervention that reduces stress in people who combine work with informal care: randomized controlled trial results. The European Journal of Public Health. 2018:485-9.

15. Araújo O, Lage I, Cabrita J, Teixeira L. Intervention in informal caregivers who take care of older people after a stroke (InCARE): study protocol for a randomised trial. Journal of advanced nursing. 2015:2435-43.

16. Allen RS, M.M H, Ege MA, Shuster JL, Burgio LD. Legacy activities as interventions approaching the end of life. Journal of Palliative Medicine. 2008:1029-38.
17. Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database for Systematic Reviews. 2011.

18. Lopez-Hartmann M, Wens J, Verhoeven V, Remmen R. The effect of caregiver support interventions for informal carers of community-dwelling frail elderly: a systematic review. International Journal of Integrated Care. 2012.

19. George LK, Gwyther LP. Caregiver well-being: a multidimensional examination of family caregivers of demented adults. The Gerontologist. 1986:253–9.

20. Bastawrous M. Caregiver burden - A critical discussion. International Journal of Nursing Studies. 2013:431–41.

21. Montgomery RJV, Gonyea JG, Hooyman NR. Caregiving and the Experience of Subjective and Objective Burden. Family Relations. 1985:19–26.

22. Lazarus RS, Folkman S. Stress, Appraisal and Coping. New York: Springer; 1984.

23. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the Stress Process: An Overview of Concepts and Their Measures. The Gerontologist. 1990:583–94.

24. Biddle BJ. Recent developments in role theory. Annual review of sociology. 1986:67–92.

25. Goode WJ. A theory of role strain. American sociological review. 1960:483–96.

26. Walker RV, Powers SM, Bisconti TL. Positive Aspects of the Caregiving Experience: Finding Hope in the Midst of the Storm. Women & Therapy. 2016:354–70.

27. Noonan AE, Tennstedt SL. Meaning in caregiving and its contribution to caregiver well-being. The Gerontologist. 1997:785–94.

28. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: A theoretically based approach. Journal of Personality and Social Psychology. 1989:267–83.
29. Cooper C, Balamurali TBS, Livingston G. A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. International Psychogeriatrics. 2006:175–95.

30. Li R, Cooper C, Bradley J, Shulman A, Livingston G. Coping strategies and psychological morbidity in family carers of people with dementia: A systematic review and meta-analysis. Journal of Affective Disorders. 2012:1-11.

31. Perez-Ordóñez F, Frías-Osuna A, Romero-Rodríguez Y, Del-Pino-Casado R. Coping strategies and anxiety in caregivers of palliative cancer patients. European Journal of Cancer Care. 2016:600-7.

32. Gilhooly KJ, Gilhooly MLM, Sullivan MP, McIntyre A, Wilson L, Harding E, et al. A meta-review of stress, coping and interventions in dementia and dementia caregiving. BMC Geriatrics. 2016:106.

33. Savage S, Bailey S. The impact of caring on caregivers’ mental health: a review of the literature. Australian Health Review. 2004:111-7.

34. Thompson EH, Futterman AM, Gallagher-Thompson D, Rose JM, Lovett SB. Social Support and Caregiving Burden in Family Caregivers of Frail Elders. Journal of Gerontology. 1993:S245-S54.

35. Vandepitte S, Van Den Noortgate N, Putman K, Verhaeghe S, Verdonck C, Annemans L. Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review. Geriatric Psychiatry. 2016:1277-88.

36. Laporte Uribe F, Heinrich S, Wolf-Ostermann K, Schmidt S, Thyrian JR, Schäfer-Walkmann S, et al. Caregiver burden assessed in dementia care networks in Germany: findings from the DemNet-D study baseline. Aging & mental health. 2017:926-37.*

37. Guerriere D, Husain A, Zagorski B, Marshall D, Seow H, Brazil K, et al. Predictors
of caregiver burden across the home-based palliative care trajectory in Ontario, Canada. Health & Social Care in the Community. 2016:428–38.*

38. Lethin C, Leino-Kilpi H, Bleijlevens MHC, Stephan A, Martin MS, Nilsson K, et al. Predicting caregiver burden in informal caregivers caring for persons with dementia living at home - A follow-up cohort study. Dementia. 2018.*

39. Ransmayr G, Hermann P, Sallinger K, Benke T, Seiler S, Dal-Bianco P, et al. Caregiving and Caregiver Burden in Dementia Home Care: Results from the Prospective Dementia Registry (PRODEM) of the Austrian Alzheimer Society. Journal of Alzheimer’s Disease: JAD. 2018:103–14.*

40. Braich PS, Jackson M, Knohl SJ, Bhoiwala D, Gandham SB, Almeida D. Burden and Depression in Caregivers of Blind Patients in New York State. Ophthalmic Epidemiology. 2016:162–70.*

41. de Almeida Mello J, Macq J, Van Durme T, Cès S, Spruytte N, Van Audenhove C, et al. The determinants of informal caregivers’ burden in the care of frail older persons: a dynamic and role-related perspective. Aging & Mental Health. 2017:838–43.*

42. Flyckt L, Fatouros-Bergman H, Koernig T. Determinants of subjective and objective burden of informal caregiving of patients with psychotic disorders. International Journal of Social Psychiatry. 2015:684–92.*

43. Hsu T, Loscalzo M, Ramani R, Forman S, Popplewell L, Clark K, et al. Factors associated with high burden in caregivers of older adults with cancer. Cancer. 2014:2927–35.*

44. Riffin C, Van Ness PH, Wolff JL, Fried T. Multifactorial Examination of Caregiver Burden in a National Sample of Family and Unpaid Caregivers. Journal of the American Geriatrics Society. 2018.*
45. Blanthorn-Hazell S, Gracia A, Roberts J, Boldeanu A, Judge D. A survey of caregiver burden in those providing informal care for patients with schizophrenia or bipolar disorder with agitation: results from a European study. Annals of general psychiatry. 2018:8.*

46. Fridman M, Banaschewski T, Sikirica V, Quintero J, Erder MH, Chen KS. Factors associated with caregiver burden among pharmacotherapy-treated children/adolescents with ADHD in the Caregiver Perspective on Pediatric ADHD survey in Europe. Neuropsychiatric Disease and Treatment. 2017:373-86.*

47. Del-Pino-Casado R, Pérez-Cruz M, Frías-Osuna A. Coping, subjective burden and anxiety among family caregivers of older dependents. Journal of Clinical Nursing. 2014:3335-44.*

48. Polenick CA, Martire LM. Caregiver attributions for late-life depression and their associations with caregiver burden. Family process. 2013:709-22.*

49. Juntunen K, Salminen A-L, Törmäkangas T, Tillman P, Leinonen K, Nikander R. Perceived burden among spouse, adult child, and parent caregivers. Journal of Advanced Nursing. 2018:2340-50.*

50. Unson C, Flynn D, Haymes E, Sancho D, Glendon MA. Predictors of types of caregiver burden. Social Work in Mental Health. 2016:82-101.*

51. Cohen SA, Cook S, Kelley L, Sando T, Bell AE. Psychosocial factors of caregiver burden in child caregivers: results from the new national study of caregiving. Health and Quality of Life Outcomes. 2015:120.*

*Article that is included in the review.

Table 1

Table 1 Search strategy (as conducted on 31st of January 2019).
| Database           | Search strategy                                      | Hits    |
|--------------------|------------------------------------------------------|---------|
| Medline & PsycINFO | #1 TI caregiver OR TI carer OR TI caregiving        | 37,659  |
|                    | #2 Informal OR family OR spouse OR partner OR relative | 2,756,180 |
|                    | #3 TI burden OR TI stress OR TI strain OR TI burnout OR TI overstrained | 450,956 |
|                    | #4 Determinants OR factors OR causes OR reasons      | 6,905,652 |
|                    | #5 #1 AND #2 AND #3 AND #4                          | 1,601   |
|                    | #6 Limit #4 to English AND from 2013 onwards         | 659     |
| Scopus             | #1 TI caregiver OR TI carer OR TI caregiving        | 28,197  |
|                    | #2 Informal OR family OR spouse OR partner OR relative | 4,048,355 |
|                    | #3 TI burden OR TI stress OR TI strain OR TI burnout OR TI overstrained | 744,861 |
|                    | #4 Determinants OR factors OR causes OR reasons      | 10,995,149 |
|                    | #5 #1 AND #2 AND #3 AND #4                          | 1,049   |
|                    | #6 Limit #5 to English AND from 2013 onwards         | 459     |

**Figures**
Figure 1

Adapted Stress Model

Figure 2

Flow diagram of the selection process
Supplementary Files

This is a list of supplementary files associated with the primary manuscript. Click to download.

Appendix 1 Output literature review.docx