

The internal and external validation of the caregiver burden model of caregivers of community-dwelling frail older persons

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Abstract

Title. The internal and external validation of the caregiver burden model of caregivers of community-dwelling frail older persons.

Background. With the ageing of the population, the number of informal caregivers of community-dwelling frail older persons will grow. Informal caregiving is associated with adverse outcomes, such as financial burden, depression and even mortality. It is desirable to identify informal caregivers at risk for caregiver burden and provide preventive care. A model to predict caregiver burden was developed, however validation was needed.

Aim. The aim is to internal and external validate the previously developed model for caregiver burden in informal caregivers of community-dwelling frail older persons and to develop a tool for healthcare professionals.

Method. Secondary data-analyses of the U-PROFIT (internal validation dataset) and TOPICS-MDS (external validation dataset) were used. The original caregiver burden model was adjusted using backwards multivariate logistic regression. The calibration and discrimination were assessed using the Hosmer-Lemeshow goodness-of-fit test and the Area under the Receiver Operating Curve (AUC). The predictive accuracy was calculated for the developed scorecard.

Results. The validation of the original model resulted in a adjusted model with four significant predictors; relational problems, mental health problems, problems of combining care tasks with daily activities and functional limitations of the care receiver. The model showed an AUC of 0.81 (95%CI, 0.75-0.87) at the internal validation and an AUC of 0.73 (95%CI, 0.70-0.77) at the external validation. The developed scorecard with three predictors performed best at a cut-off value of ≥ 16 .

Conclusion. The original caregiver burden model was adjusted into a final model. The final model performed excellent at the internal validation and acceptable at the external validation.

Recommendations. Further research to the feasibility and performance of the scorecard in practice is recommended.

Keywords. *Informal caregivers, caregiver burden, community-dwelling frail older persons, prediction model, validation.*

Samenvatting

Titel. De interne en externe validatie van het mantelzorgmodel voor het voorspellen van mantelzorgoverbelasting bij mantelzorgers van thuiswonende kwetsbare ouderen.

Achtergrond. Door het vergrijzen van de populatie zal het aantal mantelzorgers van thuiswonende kwetsbare ouderen toenemen. Mantelzorgoverbelasting wordt geassocieerd met nadelige gevolgen, zoals financiële lasten, depressie en zelfs mortaliteit. Het is wenselijk om mantelzorgers met een hoog risico op mantelzorgoverbelasting te identificeren zodat preventieve interventies kunnen worden ingezet. Een prognostisch model voor mantelzorgoverbelasting is al ontwikkeld, echter is de validiteit van het model nog niet geëvalueerd.

Doel. Het doel is het intern en extern valideren van het eerder ontwikkelde model voor het voorspellen van mantelzorgoverbelasting bij mantelzorgers van thuiswonende kwetsbare ouderen en het ontwikkelen van een instrument voor zorgverleners.

Methode. Voor deze studie werden secundaire data-analyses van de U-PROFIT (interne validatie dataset) en TOPICS-MDS (externe validatie dataset) gebruikt. Het originele model werd aangepast met behulp van backwards multivariate logistische regressie. De kalibratie en discriminatie werden bepaald met behulp van de Hosmer-Lemeshow goodness-of-fit test en de Area under the Receiver Operating Curve (AUC). De predictieve waarden van de scorekaart werden bepaald.

Resultaten. De validatie van het originele model, resulteerde in een aangepast model met vier significante predictoren: relationele problemen, psychische problemen, problemen met het combineren van de zorgtaken en de dagelijkse activiteiten, en functionele beperkingen van de oudere. Bij de interne validatie was de AUC 0.81 (95%CI, 0.75-0.87), bij de externe validatie was de AUC 0.73 (95%CI, 0.70-0.77). De ontwikkelde scorekaart met drie predictoren presteerde optimaal bij een afkapwaarde van ≥ 16 punten.

Conclusie. Het originele model werd aangepast en resulteerde in een model dat excellent presteerde bij de interne validatie en acceptabel bij externe validatie.

Aanbevelingen. Vervolgonderzoek naar de toepasbaarheid van de scorekaart in de praktijk wordt aanbevolen voordat het geïmplementeerd wordt.

Trefwoorden. *Mantelzorgers, mantelzorgoverbelasting, validatie, predictiemodel, thuiswonende kwetsbare ouderen.*

Introduction

Nowadays approximately 90% of long-term care is provided by informal caregivers¹. Informal caregivers are closely related to the care receiver, and provide non-professional care to their relative, neighbour or friend². Worldwide the percentages of informal caregivers on population level range from 10% to 33%³⁻⁶. This wide range is seen because of the various methods of the operationalization of informal caregiving and various cultural influences⁵. With the ageing of the population it is expected that the number of caregivers will grow.

Being an informal caregiver is associated with feelings of satisfaction⁷, emotional reward and personal growth⁸. However, 14.3% to 40% of the informal caregivers experience caregiver burden⁹. Caregiver burden is by Zarit et al. (1986) defined as “the extent to which caregivers perceive that caregiving has an adverse effect on their emotional, social, financial, physical, and spiritual functioning”¹⁰. It has been shown that informal caregiving is associated with less leisure time, lower income and higher costs¹¹. Thereby, caring for close relatives can result in higher stress levels^{12,13} and depression¹⁴. Next to this, informal caregivers who are caring for their spouses and already experience caregiver burden, have a higher risk of mortality within four years¹⁵.

Providing preventive care to informal caregivers at risk for caregiver burden can only be done if caregivers at risk can be identified. However, a validated prediction model or practical tool is lacking. Many papers described the risk factors for caregiver burden of homogenous diagnostic populations, like stroke patients^{16,17} or patients with dementia¹⁸⁻²¹. Known risk factors for caregiver burden of caregivers of stroke patients are hours of informal care, the number of caregiving tasks^{16,17}, mental health of the caregiver¹⁶, health-related quality of life (QoL) and the patient’s age¹⁷. For caregivers of dementia patients, risk factors of caregiver burden are coping strategies, hours of informal care^{20,21}, impairments in the instrumental activities of daily living (IADL)²⁰ and activities of daily living (ADL)^{18,20}, co-residence²⁰, self-rated health status²¹, and the severity of dementia¹⁸.

However, the homogeneity of the populations under former research, limits the generalizability to informal caregivers of community-dwelling frail older persons^{22,23}. Yet the number of community-dwelling frail older persons will increase with the ageing of the population²⁴. Frailty is defined as “a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social) that are caused by the influence of a range of variables and which increases the risk of adverse outcomes”²⁵.

To identify the risk factors of caregiver burden for caregivers of these community-dwelling frail older persons, one recent study was conducted. This study resulted in the development of a prognostic model consisting of two significant predictors: ‘problems of

combining caregiver tasks with the daily activities of the informal caregiver' (OR, 2.82; 95% CI, 1.50-5.29) and 'the functional limitations of the care receiving community-dwelling older person' (OR, 1.14; 95%CI, 1.02-1.26)²⁶. However, the performance of the model was not assessed. The performance can be distinguished in the internal and external validation, which are important steps before a model can be presented to the clinical practice²⁷. The internal validation refers to the reproducibility of the model in the sample it was derived from²⁷⁻²⁹. After assessing the internal validation, the prognostic model needs examination in a broader sample, because the performance can differ from its performance in the development sample^{28,30}, i.e. external validation²⁷⁻²⁹. After assessing the external validation, the prognostic model can be converted to a practical tool for healthcare professionals²⁷, allowing healthcare professionals to identify informal caregivers of community-dwelling frail older persons at risk for caregiver burden and provide preventive care.

Aim

The aim of this study is to internal and external validate the previously developed prognostic model for caregiver burden in informal caregivers of community-dwelling frail older persons and to develop a practical tool for healthcare professionals to predict caregiver burden.

Method

Design

This study had a prognostic study design. This design was chosen because the original caregiver burden model is a prediction model. The validation of the model and development of a prediction tool belong to the prognostic research within the epidemiologic designs³¹. To determine the internal and external validation, secondary data-analyses of longitudinal prospective studies with quantitative designs were used^{32,33}.

Population and domain

Internal validation sample.

The population of the internal validation sample consisted of dyads of informal caregivers and community-dwelling frail older persons living in the Netherlands. Data of the *Utrecht PROactive Frailty Intervention Trial* (U-PROFIT) was used to determine the internal validation. Informal caregivers were eligible to participate in the U-PROFIT if they were providing care to a community-dwelling frail older person, referred to as care receivers³³. Care receivers were eligible to participate if they were 60 years and older, living independently in the community and were frail. Frailty was defined as a frailty index score of

≥0.20, using chronically five or more different medications and/or having a consultation gap in primary care of three years or more³³.

External validation sample.

The population of the external validation sample consisted of dyads of informal caregivers and community-dwelling frail older persons living in the Netherlands. To determine the external validation, data of *The Older Persons and Informal Caregivers Survey - Minimum Data Set* (TOPICS-MDS) was used³². The TOPICS-MDS is a compromised database with multiple Dutch studies, for this study a composite sample with data of seven studies was used³⁴⁻⁴⁰. The informal caregivers in this composite sample were included if they were providing care to a community-dwelling frail older person (e.g. care receiver). The care receivers in the composite sample were 70 years and older, living independently in the community and frail. Frailty was defined as a frailty index score of ≥0.20, measured with the Short TOPICS-Frailty Index⁴¹.

Data collection

Internal validation sample.

The data of the internal validation sample was gathered in the U-PROFIT trial, conducted from October 2010 till March 2012 in the Netherlands. The collected data consisted of socio-demographic characteristics and multiple self-reported measurements of the informal caregivers and care receivers at baseline and 12 months follow-up³³.

External validation sample.

The data of the external validation sample consisted of data from seven prospective quantitative studies³⁴⁻⁴⁰. These studies were conducted from 2010 till 2014 in the Netherlands. The socio-demographic characteristics and multiple self-reported measurements from the informal caregivers and their care receivers at baseline and 12 months follow-up were used for this study. The self-reported measurements were identical to the self-reported measurements of the internal validation sample³².

Outcome.

Caregiver burden was the primary outcome of interest, measured at 12 months follow-up with the Self-Rated Burden scale (SRB)⁴². Caregivers were asked to rate their feelings in caring for the frail older person, on a scale of 0-10 ('not at all straining' to 'much too straining')⁴³. Caregiver burden was defined as a SRB score of 6 and higher²⁶. The other study outcomes were the performance of the caregiver burden model, assessed by measurements of calibration and discrimination.

Candidate predictors.

The original model was build using multiple candidate predictors chosen from the literature and clinical reasoning²⁶. The candidate predictors consisted of measurements of informal caregivers as well as care receivers (table 1).

The care-related quality of life (QoL) of the informal caregivers was measured with the validated CarerQoL, which consists of the CarerQoL-7D and the CarerQoL-VAS⁴⁴. The CarerQoL-7D measures seven dimensions; care-related fulfilment, relational problems with the care receiver, mental health problems, problems of combining care tasks with daily activities, financial problems, social support and physical health problems. On a single item per dimension caregivers indicate to what extent the dimension is affecting their personal situation⁴⁴. The CarerQoL-VAS is a visual analogue scale to rate the caregiver's happiness (range 0-10).

Two modified questions of the RAND-36 concerning health perceptions were used to measure the health-related QoL^{32,33}. The RAND-36 is validated for the Dutch population⁴⁵, and has a moderate to strong reliability and homogeneity⁴⁶.

To assess the self-perceived QoL of informal caregivers and care receivers, a modified version of Cantril's Self Anchoring Ladder was used⁴⁷. Participants were asked to rate their current life on a scale of 0-10^{32,33}.

Functional limitations of the care receivers were measured with the modified Katz-15 index⁴⁸. It comprises the basic Activities of Daily Living (ADL)⁴⁹ and Instrumental Activities of Daily Living (IADL)⁵⁰ in one instrument. The needed assistance is measured on six ADL functions (bathing, dressing, eating, using a toilet, use of incontinence products, getting up from a chair) and nine IADL functions (grooming, use of telephone, travelling, walking, grocery shopping, meal preparation, household tasks, taking medications, financial management). The modified Katz-15 index had a range of 0-15, where a higher score meant the care receiver needed more assistance.

TABLE 1

Procedures

This study used three phases in the procedures. At first the internal validation was assessed and if necessary, adjustments on the original model were made. Secondly, the external validation of the final model was assessed in the external validation sample. Thirdly, a practical tool was developed based on the regression coefficients of predictors of the external validation.

Ethical issues

This study was conducted according to the principles of the Declaration of Helsinki (2013)⁵¹ and the Code of Conduct for Health Research⁵².

The U-PROFIT was approved by the research ethics committee of the University Medical Centre Utrecht (UMC Utrecht) and is registered with trial number: NTR2288³³. Consent for using the fully anonymous data was given by the principal investigator. The data of the TOPICS-MDS are also fully anonymous. Therefore using the data for a secondary data-analysis falls outside the remit of the Medical Research Involving Human Subjects Act (WMO) (Radboud University Medical Center Ethical Committee review reference number: CMO: 2012/120).³²

Data analysis

The data were analysed using IBM SPSS version 22, Armonk NY, USA. Before starting the initial analysis, the data was checked for errors, outliers, normality and multicollinearity. The candidate predictors concerning general health and QoL were recategorized from five into three categories; excellent/very good (1), good (2), fair/poor (3). To perform an adequate analysis, the answering categories of the CarerQoL were dichotomised into the values 'none' (0) versus 'some / a lot of' (1).

The internal validation was assessed by reconducting all the steps of the development of the original caregiver burden model. Therefore an univariate logistic regression was conducted on all the candidate predictors, followed by the backwards selection of the predictors of caregiver burden. The Akaike Information Criterion (AIC) was used as the stopping rule for the inclusion of the predictors with $p=0.157$ ²⁶. For the final model, the multivariate logistic regression using the enter method with complete case analysis was performed.

The external validation was assessed by conducting a multivariate logistic regression (enter method) with the predictors of the final model on the external validation sample.

The calibration was assessed with the Hosmer-Lemeshow goodness-of-fit test. The Hosmer-Lemeshow goodness-of-fit test compares observed and predicted numbers of caregiver burden in groups, with a Chi-square test⁵³.

The discrimination of the model refers to the extent in which the model distinguishes caregivers with caregiver burden and those without caregiver burden⁵⁴. The discrimination was assessed with the Area under the Receiver Operating Curve (AUC). For binary outcomes the AUC is equivalent to the concordance statistics^{53,55}. The values of the AUC are between 0.5-1.0, where 0.5 indicates the model does not discriminate, and 1.0 indicates the model discriminates perfectly⁵⁵. For prognostic models the AUC regularly lies between 0.60-0.85⁵⁶. The AUC was presented with 95% confidence interval (CI).

The practical scorecard was developed by using the beta regression coefficients from the external validation, multiplied by 10 or more and rounded⁵³. Next to this, a risk score per caregiver of the external validation sample was calculated. Followed by analysing the clinical usefulness in terms of sensitivity, specificity, positive predicted value and negative predicted value for multiple cut-off scores²⁷.

Results

Internal validation.

The internal validation sample consisted of 335 dyads of informal caregivers and care receivers. The mean age of the caregivers was 63.3 years (SD=12.7) and most caregivers were female (N=239, 71.3%) (table 2). Caregiver burden was experienced by 30.1% (N=101) informal caregivers at 12 months. The mean age of the care receivers was 78.4 years (SD=8.7), 193 (57.6%) were female (table 3). A number of 97 (29%) informal caregivers had missing values on the outcome of interest (SRB) at twelve months. Therefore these respondents were excluded from further analysis. Of the remaining 238 informal caregivers and care receivers, 1.3% had missing values on one of the candidate predictors.

The results of the univariate analysis confirmed the candidate predictors which were chosen to develop the caregiver burden model. The backwards multivariate logistic regression resulted in a model with eight predictors of caregiver burden. Six predictors were items of the CarerQol and related to the caregiver; fulfilment of caregiving (OR, 0.13; 95% CI, 0.02-0.75), relational problems (OR, 1.68; 95% CI, 0.83-3.40), mental health problems (2.07; 95% CI, 1.05-4.08), problems of combining care tasks with daily activities (OR, 2.53; 95% CI, 1.29-4.97), financial problems (OR, 3.99; 95% CI, 0.99-16.05) and social support (OR, 0.51; 95% CI, 0.25-1.04). The other two predictors were related to the care receivers; the Katz-15 index score (OR, 1.28; 95% CI, 1.13-1.44) and age (OR, 1.05; 95% CI, 1.01-1.09) (table 4). The discrimination of model was excellent with a significant AUC of 0.81 (95% CI, 0.75-0.87). The calibration had a non-significant Chi-square of 7.18 with 8 degrees of freedom, which means no significant differences between the observed and predicted cases of caregiver burden were found. The overall correct predicted caregiver burden was 72.4%, the sensitivity was 63.5% and the specificity was 79.2% (table 5).

TABLE 2 AND 3

External validation.

The external validation sample consisted of 797 informal caregivers and their care receivers. The mean age of the informal caregivers was 63.4 years (SD=13.1), 463 (58.1%) informal caregivers were female (table 2). The prevalence of caregiver burden at 12 months

was 32.2% (N=257). The mean age of the care receivers was 82.6 years (SD=5.8), 540 (67.8%) was female (table 3). The sample had 8.2% of missing values on the predictors of the informal caregivers and 0.3% of missing values on the predictors of the care receivers.

From the eight predictors of the final model, the multivariate logistic regression showed significance in just four predictors, three of those were items of the CarerQol; relational problems (OR, 2.26; 95% CI, 1.59-3.22), mental health problems (OR, 1.67; 95% CI, 1.16-2.39), problems of combining care tasks with daily activities (OR, 2.22; 95% CI, 1.55-3.18). The other significant predictor was related to the care receiver; the Katz-15 index score (OR, 1.09; 95% CI, 1.03-1.15). The other four predictors of the model were not significant in the external validation sample (table 4). The discrimination was acceptable with a significant AUC of 0.73 (95%CI, 0.70-0.77). The calibration was also acceptable with a non-significant Chi-square of 5.22 with eight degrees of freedom (table 5), indicating no significant differences between the observed and predicted cases of caregiver burden were found. The model showed an overall corrected predicted percentage of caregiver burden of 70.3%, with a sensitivity of 34.9% and a specificity of 87.7%.

TABLE 4 AND 5

Practical scorecard.

The developed scorecard was initially based on four significant predictors of the external validation. One of the four predictors was the Katz-15 index score of the care receiver. The other three predictors were questions, which needed to be answered by the caregiver. The beta coefficients of these predictors were multiplied by 12.5 and rounded. The clinical usefulness of multiple cut-off values was determined by calculating the sensitivity, the specificity, the positive and negative predictive values, and the percentage of correct predicted cases of caregiver burden. However, the usage in practice of the scorecard seemed suboptimal because questions needed to be answered by the informal caregiver as well as the care receiver. It would be more practical if the questions only had to be answered by the informal caregiver. Therefore, the clinical usefulness of a short version of the scorecard (without the Katz-15 index score) was also calculated for multiple cut-off values (table 7). The performance was very similar to the initial scorecard (not shown). Because of its applicability, the short version was preferred (table 6). The values of the scorecard ranged from 0-26. The scorecard showed the best accuracy at a cut-off value of 16, indicating that informal caregivers with a score of 16 and higher, had a risk of 66,7% on developing caregiver burden in the next 12 months.

TABLE 6 AND 7

Discussion

This study was conducted to internal and external validate the previously developed caregiver burden model and develop a practical scorecard for healthcare professionals. At the internal validation, the multivariate logistic regression resulted in a final model with eight predictors of caregiver burden. This final model performed excellent at the apparent internal validation. At the external validation, the accuracy was slightly less, but still acceptable. Four predictors remained significant; relational problems, mental health problems, problems of combining care tasks with daily activities and the functional limitations of the care receiver. For practical reasons, the scorecard was built on three predictors concerning the informal caregiver. The scorecard showed the best accuracy when a cut-off value of ≥ 16 was used.

Comparing the results of the current study with other literature, the four significant predictors found in this study are mainly consistent with the results of other studies. The predictor 'relational problems' was in line with the findings of a cross-sectional study to the problems experienced by informal caregivers of community-dwelling older persons. They found social-relational problems, such as the role changing aspects of informal caregiving, are frequently mentioned problems by the informal caregiver and have a high impact on caregiving⁵⁷.

The predictor 'mental health problems' of the informal caregiver was confirmed by other studies. Reviews of informal caregivers of stroke patients and patients with dementia, showed that caregivers with poor mental or psychological health, anxiety and depressive symptoms experienced more caregiver burden^{16,18}. Other research confirmed the correlation between caregiver's anxiety and caregiver burden⁵⁸.

The predictor 'caregiver's problems of combining care tasks with their daily activities' was less frequently studied. However, one recent study of Oldenkamp et al. (2016) found problems of combining care tasks with daily activities negatively influenced caregiver burden in spouses as well as adult-child caregivers⁵⁹. Adult-child caregivers frequently had to combine their care tasks with working-life and their own family⁶⁰. Therefore, it seemed plausible this was a predictor for caregiver burden.

The association between functional limitations of the care receiver and caregiver burden was frequently studied. Similar to the results of the present study, most studies showed significant associations between the functional limitations of the care receiver and caregiver burden^{20,61,62}. One study did not report significant associations, but this might be due to the small sample size of this study⁶³.

Although four significant predictors of caregiver burden were found in this study, some predictors, such as hours of informal care^{16,17,20,21}, did not result as a predictor in this

study. Most studies focused just on the hours of informal care, and not to what extent the informal caregiver could fit their hours of informal care into their daily activities⁶⁷. It is likely, that informal caregivers who provided many hours of informal care, had more problems to combine their care tasks with their daily activities. In the current study, both were included, and it appeared that problems of combining care tasks with daily activities was a predictor, probably at the expense of hours of informal care.

To our knowledge this study was the first study which succeeded to develop and validate a prognostic model to predict caregiver burden. One of the strengths of this study, was the combination of internal and external validation of the model, because although many prediction models were developed and internal validated, the external validation was frequently lacking²⁸. With assessing the external validation, the generalization of the model was demonstrated²⁸. Another strength was the sample size of this study. The samples of prognostic research should at least contain five events per candidate predictor⁶⁸. The samples of this study had respectively 101 and 257 informal caregivers with caregiver burden in the internal and external validation sample, and therefore were sufficient to apply prognostic research. Finally, a strength of the current study was the development of a scorecard, allowing healthcare professionals to easily use the prognostic model. The use in practice was considered at the development of the scorecard, by determining the clinical usefulness of two versions. This resulted in a scorecard with three questions to the informal caregiver. This increased the usability for healthcare professionals.

Besides strengths, the current study had some limitations. Firstly, on both samples complete case analysis were applied, which might led to selection bias. However, the remaining sample sizes were still appropriated and achieved the required five events per variable⁶⁸. Secondly, this study was a secondary data-analysis. Although many characteristics and measurements were available of the caregivers and community-dwelling frail older persons, it was not possible to perform additional measurements with more sensitive measurement tools for measuring the caregivers mental health problems, or the functional limitations of the care receivers. Thirdly, this study was performed using data from the Netherlands only. Therefore, the final model and scorecard cannot be applied in other countries before assessing its predictive performance in other populations.

Further research should focus on the transferability of the final model to other populations in Western countries. With regard to the scorecard, further research is needed to determine the feasibility and performance in practice. If the scorecard performs well in practice, healthcare professional will have an easy instrument for screening informal caregivers of community-dwelling frail older persons for the risk of caregiver burden.

In conclusion, the original caregiver burden model was adjusted into a final model with eight predictors. The final model performed excellent at the internal validation and

acceptable at the external validation. Four predictors remained significant at the external validation. For practical reasons, three of those were transformed into an easy scorecard for healthcare professionals. Research to the feasibility and performance of the scorecard in practice is recommended as a next step.

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Tables

Table 1

Candidate predictors

Informal caregivers			
Candidate predictor	Measured by	Operationalisation	Type of outcome
Relation	The caregiver's relationship with the care receiver	- Husband / wife / life partner - Sister / brother / brother in law / sister in law - Daughter (in law) / son (in law) - Other, namely	Nominal
	Whether the caregiver lived together with the care receiver	Yes / No	Binary
Objective burden	Informal care: - household tasks - personal care - transport or financial / administrative duties	Yes / No	Binary
Health	RAND-36 (2 question) - General health - General health compared to a year ago	1-5; Excellent (1) – poor (5) 1-5; Much better (1) – much worse (5)	Ordinal ^a
Quality of life	Cantril's Self Anchoring Ladder	0-10; higher score = better quality of life	Continuous
	RAND-36 (2 adjusted questions) - General quality of life - General quality of life compared to a year ago	1-5; Excellent (1) – poor (5) 1-5; Much better (1) – much worse (5)	Ordinal ^a
Care-related quality of life	CarerQoI-7D	1-3; No (1), some (2), a lot (3)	Ordinal ^b
	CarerQoI-VAS	0-100; higher score = more happy	Continuous
Community-dwelling frail older persons			
Candidate predictor	Measured by	Operationalisation	Type of outcome
Quality of life	Cantril's Self Anchoring Ladder (adjusted)	1-10; higher score = better quality of life	Continuous
Functional limitations	Katz-15 score	0-15; higher score = more assistance needed	Continuous

Note. ^a = recategorized into 3 categories before analysis. ^b = dichotomised before analysis.

Table 2*Baseline characteristics and univariate logistic regression of the informal caregivers*

	Internal validation sample N=335			External validation sample N=797		
		Univariate OR [95% CI]	<i>p</i>		Univariate OR [95% CI]	<i>p</i>
Gender (female), <i>n</i> (%) <i>Missing values, n</i> (%)	239 (71.3) 0 (0,0)	1.17 [0.65; 2.10]	.606	463 (58.1) 134 (16.8)	1.47 [1.02; 2.12]	.037
Age (years), <i>mean</i> (<i>SD</i>) <i>Missing values, n</i> (%)	63.3 ±12.7 0 (0.0)	1.01 [0.99; 1.03]	.252	63.4 ±13.1 136 (17.0)	1.00 [0.99; 1.02]	.522
Relationship, <i>n</i> (%) <i>Missing values, n</i> (%)	1 (0.3)			2 (0.3)		
- Husband / wife / life partner	159 (47.5)	*	.571	259 (32.5)	*	.417
- Daughter / son (in law)	130 (38.8)	0.30 [0.03; 2.72]	.282	436 (54.7)	0.48 [0.15; 1.48]	.198
- Brother / sister (in law)	6 (1.8)	0.82 [0.47; 1.43]	.480	19 (2.4)	0.83 [0.60; 1.14]	.247
- Other	39 (11.6)	0.67 [0.27; 1.62]	.370	81 (10.2)	0.76 [0.44; 1.31]	.330
Living together with the care receiver, <i>n</i> (%) <i>Missing values, n</i> (%)	177 (52.8) 2 (0.6)	1.63 [0.97; 2.76]	.066	414 (51.8) 8 (1.0)	1.06 [0.79; 1.43]	.702
Time spent at caregiving, <i>n</i> (%)						
Household tasks <i>Missing values, n</i> (%)	275 (82.1) 1 (0.3)	1.75 [0.84; 3.67]	.136	570 (71.5) 85 (10.7)	1.32 [0.88; 1.97]	.177
Personal care <i>Missing values, n</i> (%)	122 (36.4) 1 (0.3)	2.94 [1.69; 5.13]	.000	209 (26.9) 25 (3.1)	2.36 [1.70; 3.28]	.000
Outside activities <i>Missing values, n</i> (%)	258 (77.0) 2 (0.6)	2.02 [1.04; 3.94]	.039	656 (82.3) 20 (2.5)	1.65 [1.05; 2.58]	.029
Support of others <i>Missing values, n</i> (%)	109 (32.5) 2 (0.6)	1.03 [0.59; 1.79]	.920	303 (38.0) 29 (3,6)	0.98 [0.72; 1.34]	.908
General health, <i>n</i> (%) <i>Missing values, n</i> (%)	3 (0.9)			1 (0.1)		
- Excellent / Very good	90 (26.9)	*	.039	197 (24.7)	*	.000
- Good	140 (41.8)	1.93 [1.00; 3.72]	.050	394 (49.4)	1.46 [0.98; 2.17]	.064
- Fair / Poor	102 (30.4)	2.50 [1.21; 5.14]	.013	205 (25.7)	2.89 [1.88; 4.46]	.000
General health year ago <i>Missing values, n</i> (%)	3 (0.9)			1 (0.1)		

- Much better / Little better	31 (9.3)	*	.551	58 (7.3)	*	.000
- Same	252 (75.2)	0.79 [0.34; 1.86]	.592	601 (75.4)	0.99 [0.55; 1.79]	.970
- Slightly worse / Much worse	49 (14.6)	1.18 [0.40; 3.47]	.761	137 (17.2)	2.34 [1.21; 4.52]	.011
General QoL score, <i>mean(SD)</i> <i>Missing values, n(%)</i>	7.27 ± 1.22 5 (1.5)	0.62 [0.49; 0.79]	.000	7,46 ± 1.020 147 (18.4)	0.71 [0.60; 0.83]	.000
General QoL, <i>n(%)</i> <i>Missing values, n(%)</i>	4 (1.2)			2 (0.3)		
- Excellent / Very good	109 (32.5)	*	.000	271 (34.0)	*	.000
- Good	152 (45.4)	1.12 [0.61; 2.06]	.717	408 (51.2)	1.70 [1.20; 2.42]	.003
- Fair / Poor	70 (20.9)	5.95 [2.66; 13.32]	.000	116 (14.6)	3.23 [2.03; 5.12]	.000
General QoL year ago, <i>n(%)</i> <i>Missing values, n(%)</i>	4 (1.2)			3 (0.4)		
- Much better / Little better	46 (13.7)	*	.195	87 (10.9)	*	.000
- Same	228 (68.1)	1.82 [0.86; 3.85]	.115	591 (74.2)	1.02 [0.62; 1.68]	.924
- Slightly worse / Much worse	57 (17.0)	2.22 [0.89; 5.53]	.086	116 (14.6)	2.61 [1.45; 4.72]	.001
CarerQoI-7D, n(%)						
Fulfilment <i>Missing values, n(%)</i>	2 (0.6)			14 (1.8)		
- None	17 (5.1)	*	*	30 (3.8)	*	*
- Some / A lot of	316 (94.3)	0.23 [0.06; 0.87]	.030	753 (94.5)	0.95 [0.44; 2.06]	.894
Relational problems <i>Missing values, n(%)</i>	1 (0.3)			53 (6.6)		
- None	220 (65.7)	*	*	470 (59.0)	*	*
- Some / A lot of	114 (34.0)	3.34 [1.90; 5.89]	.000	274 (34.4)	3.27 [2.37; 4.50]	.000
Mental health problems <i>Missing values, n(%)</i>	1 (0.3)			42(5.3)		
- None	183 (54.6)	*	*	433 (54.3)	*	*
- Some / A lot of	151 (45.1)	3.28 [1.91; 5.61]	.000	322 (40.4)	2.58 [1.89; 3.52]	.000
Physical health problems <i>Missing values, n(%)</i>	0 (0.0)			37 (4.6)		

- None	158 (47.2)	*	*	357 (44.8)	*	*
- Some / A lot of	177 (52.8)	2.53 [1.49; 4.31]	.001	403 (50.6)	2.05 [1.50; 2.80]	.000
Problems combining tasks <i>Missing values, n(%)</i>	1 (0.3)			41 (5.1)		
- None	201 (60.0)	*	*	441 (55.3)	*	*
- Some / A lot of	133 (39.7)	4.39 [2.51; 7.65]	.000	315 (39.5)	3.16 [2.31; 4.33]	.000
Financial problems <i>Missing values, n(%)</i>	1 (0.3)			65 (8.2)		
- None	302 (90.1)	*	*	688 (86.3)	*	*
- Some / A lot of	32 (9.6)	4.25 [1.48; 12.22]	.007	44 (5.5)	2.55 [1.38; 4.71]	.003
Support of others <i>Missing values, n(%)</i>	4 (1.2)			22 (2.8)		
- None	167 (49.9)	*	*	263 (33.0)	*	*
- Some / A lot of	164 (49.0)	0.71 [0.42; 1.20]	.201	512 (64.2)	0.87 [0.63; 1.19]	.383
CarerQoI-VAS <i>mean(SD)</i>						
Current happiness <i>Missing values, n(%)</i>	7.1 ±1.6 2 (0.6)	0.64 [0.52; 0.80]	.000	72.0 ±13.9 7 (0.9)	0.97 [0.96; 0.99]	.000
Happiness if someone takes over the care tasks <i>Missing values, n(%)</i>	4.8 ±2.6 8 (2.4)	1.20 [1.08; 1.34]	.001	48.8 ±26.8 72 (9.0)	1.02 [1.01; 1.02]	.000

Note. QoL = Quality of Life. VAS = Visual Analogue Scale. SD = Standard Deviation. OR = Odds Ratio. 95% CI = 95% Confidence Interval. * = Reference category.

Table 3*Baseline characteristics and univariate logistic regression of the care receivers*

	Internal validation sample N=335			External validation sample N=797		
		Univariate OR [95% CI]	<i>p</i>		Univariate OR [95% CI]	<i>p</i>
Gender (female), <i>n</i> (%) <i>Missing values, n</i> (%)	193 (57,6) 18 (5.4)	0.86 [0.51; 1.47]	.583	540 (67.8) 0 (0.0)	0.76 [0.56; 1.05]	.092
Age (years), <i>mean</i> (<i>SD</i>) <i>Missing values, n</i> (%)	78.4 ±8.7 18 (5.4)	1.02 [0.99;1.05]	.183	82.6 ± 5.8 2 (0.3)	1.02 [0.99;1.05]	.112
Katz-15, <i>mean</i> (<i>SD</i>) <i>Missing values, n</i> (%)	4.4 ±3.0 18 (5.4)	1.26 [1.14; 1.40]	.000	5.3 ±3.2 0 (0.0)	1.13 [1.08; 1.19]	.000
General QoL score, <i>mean</i> (<i>SD</i>) <i>Missing values, n</i> (%)	6.6 ±1.4 20 (6.0)	0.75 [0.61; 0.91]	.005	6.9 ±1.3 61 (7.7)	0.90 [0.80; 1.01]	.064

Note. QoL = Quality of Life. SD = Standard Deviation. OR = Odds Ratio. 95% CI = 95% Confidence Interval.

Table 4*Multivariate logistic regression*

	Internal validation sample				External validation sample			
	OR [95% CI]	B	SE	<i>p</i>	OR [95% CI]	B	SE	<i>p</i>
Katz-15 score care receiver	1.28 [1.13; 1.44]	0.24	0.06	.000	1.09 [1.03; 1.15]	0.08	0.03	.004
Age care receiver	1.05 [1.01; 1.09]	0.05	0.02	.029	1.01 [0.98; 1.04]	0.01	0.02	.457
Fulfilment of caregiving*	0.13 [0.02; 0.75]	-2.02	0.88	.022	1.23 [0.53; 2.84]	0.20	0.43	.636
Relational problems*	1.68 [0.83; 3.40]	0.52	0.36	.147	2.26 [1.59; 3.22]	0.81	0.18	.000
Mental health problems*	2.07 [1.05; 4.08]	0.73	0.35	.035	1.67 [1.16; 2.39]	0.51	0.18	.005
Problems combining care tasks*	2.53 [1.29; 4.97]	0.93	0.34	.007	2.22 [1.55; 3.18]	0.80	0.18	.000
Financial problems*	3.99 [0.99; 16.05]	1.39	0.71	.051	1.46 [0.73; 2.90]	0.38	0.35	.281
Support of others*	0.51 [0.25; 1.04]	-0.67	0.36	.063	0.86 [0.60; 1.23]	-0.15	0.18	.415
Constant	0.03	-3.61	1.81	.046	0.043	-3.14	1.33	.018

Note. OR = Odds Ratio. 95% CI = 95% Confidence Interval. B = beta coefficient. SE = Standard Error. * = Items of the CarerQoI-7D.

Table 5*The performance of the final caregiver burden model*

	Classification			Discrimination		Calibration		
				AUROC		Hosmer-Lemeshow test		
	Specificity	Sensitivity	Overall correct	AUC [95% CI]	<i>p</i>	Chi-square	df	<i>p</i>
Internal validation	79.2%	63.5%	72.4%	0.81 [0.75; 0.87]	.000	7.18	8	.518
External validation	87.7%	34.9%	70.3%	0.73 [0.70; 0.77]	.000	5.22	8	.734

Note. AUC = Area under Receiver Operating Curve. 95% CI = 95% Confidence Interval. Df = degrees of freedom.

Table 6*Scorecard to predict caregiver burden*

Questions to the informal caregiver	Answer	Score
I have relational problems with the care receiver (e.g., he/she is very demanding, he/she behaves differently, we have communication problems).	No	0
	Some / A lot of	10
I have ... problems with my own mental health (e.g., stress, fear, gloominess, depression, concern about the future).	No	0
	Some / A lot of	6
I have ... problems combining my care tasks with my daily activities (e.g., household activities, work, study, family and leisure activities).	No	0
	Some / A lot of	10
Total score		

Table 7*Clinical usefulness of the scorecard*

Cut off points	Sensitivity	Specificity	Positive predicted value	Negative predicted value	Correct predictions
≥ 6	0.79	0.51	0.44	0.83	60.0%
≥ 10	0.63	0.68	0.48	0.79	65.9%
≥ 16	0.41	0.79	0.49	0.74	66.7%
≥ 20	0.32	0.82	0.47	0.71	65.9%

Note. Bold = recommended cut-off value to predict caregiver burden