

Prediction of caregiver burden in informal caregivers of frail older people.

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ABSTRACT

Background The goal of the Dutch government is to ensure that frail older people can live independently as long as possible. The proportion of frail older people will increase rapidly, therefore it is expected that the number of caregivers of frail older people at risk of caregiver burden will also increase. Caregiver burden can lead to various problems. No prediction model has been developed for caregiver burden of informal caregivers of frail older people.

Objectives To identify predictors and develop a prediction model to predict caregiver burden in informal caregivers of community dwelling frail older people.

Method The study included 358 caregivers and frail older people. Caregivers of frail older people who participated in the U-PROFIT trial were recruited. Candidate predictors and the outcome caregiver burden were measured with a questionnaire at baseline and after one year follow-up. Associations between candidate predictors and caregiver burden were examined using univariate linear regression analysis. A backward method in logistic regression resulted in a reduced model. The AUC was examined to assess the discriminative ability of the model.

Results The significant predictors in the final model were the ability to combine care tasks with the daily activities of the caregiver and having relational problems with the care receiver. The model showed an AUC of 0.68.

Conclusion The ability to combine the care tasks with the daily activities of the caregiver and having relational problems were the most important predictors for caregiver burden in caregivers of frail older people at one year follow-up. A clinical prediction model was developed.

Recommendations Future research should focus on the internal validation of the prediction model and transforming the model into a clinical useful and valid instrument that may prevent negative health outcomes for the informal caregivers.

Keywords: caregiver burden, frail older people, prediction, determinants

INTRODUCTION AND RATIONALE

In the Netherlands, there are 3.5 million informal caregivers. The number of overburdened caregivers increased from 300,000 in 2001 to 450,000 in 2008¹. An informal caregiver is a person who feels responsible for the well-being of the patient, provides unpaid care for the patient, and is closely involved in the care for the patient as non-professional^{2,3}. Informal caregiving can be intensive, especially if the caregiver also has a job³.

Informal caregivers are at risk of physical, emotional and social problems⁴⁻⁶. Caregiving may lead to financial problems and informal caregivers may have a higher risk for morbidity and mortality^{7,8}. The problems as a result of caregiving are referred to as caregiver burden. Caregiver burden is a combination of objective burden (intensity of caregiving-related demands and changes of the care receiver) and subjective burden (emotional reactions of the caregiver)⁹.

Informal caregivers play an important role in the care of frail older people. Worldwide, the proportion of frail older people (65+ years) will rapidly increase¹⁰. In the Netherlands, the proportion of older people will increase from 2,7 million in 2012 to 4,7 million in 2041¹¹. Frail older people have multiple and complex healthcare needs. Symptoms of frailty are a deterioration of activities of daily living, mobility, nutritional status, cognition and endurance. Frailty in older people often leads to disability^{12,13}. An increase in disability and especially the deterioration of cognition^{7,8} leads to an increased risk of caregiver burden among their caregivers¹⁴.

The Dutch government focuses on a preventive system in the care of frail older people. The goal of this system is to ensure that older people can live independently as long as possible and can participate in society^{3,15}. Because the proportion of frail older people will increase, it is expected that the number of informal caregivers at risk of caregiver burden will also increase¹⁶.

Several studies have shown that informal caregivers of patients with dementia, chronic illnesses, stroke and epilepsy experience caregiver burden¹⁶⁻²¹. The patients functional abilities, age, quality of life, anxiety and depression of the patient were found to be factors of the care receiver which influence caregiver burden in caregivers of patients with chronic illnesses, epilepsy and stroke¹⁷⁻²⁰. The caregivers gender, education level, the time spent at caring for the patient, travel time to the patient, age, living together with the care receiver, social support of the family and quality of live were predictors of caregiver burden in caregivers of patients with chronic illnesses, epilepsy and stroke¹⁷⁻²⁰.

Informal caregivers of frail older people also experience caregiver burden^{2,19}. A prediction model enables nurses and general practitioners (GP's) in primary care to early identify informal caregivers at risk of caregiver burden and may prevent negative health outcomes for the informal caregivers^{4,21}. Multiple studies have been conducted that

examined predictors of caregiver burden. These studies are done in multiple areas like stroke, epilepsy and dementia^{6,17,18,22}. No prediction model has been developed for caregiver burden of informal caregivers of frail older people.

OBJECTIVES

The aim of this study was to identify predictors and to develop a prediction model to predict caregiver burden in informal caregivers of community dwelling frail older people.

METHOD

Study design and population

This is a secondary data analysis. Between October 2010 and March 2012, data of the informal caregivers and care receivers were collected with one-year follow-up. The study population consisted of the caregivers of frail older people who participated in the Utrecht Primary care PROactive Frailty Intervention Trial (U-PROFIT)²³. Older people were approached by their GP and asked if they had an informal caregiver. If so, the informal caregiver was also invited to participate in the study. Recruitment for frail older people and their informal caregivers was performed in 39 clusters of primary care practices in Utrecht, the Netherlands²³. Details of enrollment procedures have been described previously²³.

No in or exclusion criteria for the caregiver were defined. The caregivers included in this study are those who provide care to frail older people (aged 60 years and over) who fulfill one or more of the following inclusion criteria:

- Multimorbidity (defined as a frailty index score of $> - 0.20$ ²³)

AND/OR

- Polypharmacy (defined as the chronic use of five or more different medications²⁴)

AND/OR

- A care gap in primary care of three or more years (defined as not having consulted the GP in the past three years, except for the yearly influenza vaccination).

Caregivers of terminally ill patients or patients living in a nursing home or assisted living facility were excluded²³.

A total of 129 caregivers were needed for this study. All patients gave written informed consent before enrolment in this study. This study has been approved by the Institutional Review Board of the University Medical Center Utrecht (UMCU).

Measurements

Characteristics of the caregivers such as age, gender and relationship of the care receiver and their informal caregiver and potential predictors were measured with the self-

reported 'baseline caregiver questionnaire' and the 'baseline care receiver questionnaire' in the U-PROFIT study. After one-year the follow-up questionnaire for both the caregiver and the care receiver was filled out. Relevant candidate predictors were chosen from the literature, clinical reasoning and current knowledge.

Main study parameter

The primary outcome is caregiver burden measured with the Self Rated Burden Visual Analogue Scale (SRB(VAS))²⁵. The SRB (VAS) ranged from 0 to 10. On this scale, informal caregivers could indicate how heavy they experience caring for the frail older patient. On this scale 0, denotes "not heavy at all" and 10 denotes "much too heavy." In this study, caregiver burden was defined as a score of ≥ 5 on the SRB(VAS) and no caregiver burden as a score of < 5 on the SRB(VAS). The correlation with other instruments (CSI, SCQ, CRA) is significant ($p < .01$), indicating that these instrument had a strong consistency²⁵. Disability and health of the patient ($p < .001$), employment and health of the caregiver ($p < .05$) and living together or not ($p < .001$) were significantly associated with the SRB²⁵.

Candidate predictors of informal caregivers

Relationship with the care receiver

The informal caregivers were asked about their relationship with the care receiver and if they lived together or not.

Health of the informal caregiver

The health of the informal caregiver was measured using the first two questions from the RAND-36 questionnaire²⁶. These questions were measured on a 5 points Likert Scale. The first question was about the general health of the caregiver ((0) excellent – (5) bad) and the second question was about the general health now, compared to a year ago ((0) much better – (5) much worse).

Time spent at caring for the care receiver

To investigate the time spent (hours per week) caring for the care receiver, informal caregivers were asked how much time they assist the care receiver with household chores, personal care, help with administration, and if they had assistance of other caregivers or volunteers.

Care-related Quality of life (CarerQoL)

The CarerQoL measures care-related quality of life in informal caregivers. The CarerQoL consist of two parts; the CarerQoL-7D and the CarerQoL-VAS. In the CarerQoL-7D, a statement was formulated to indicate the situation of the caregiver (none, some, a lot of) on the seven dimensions of the CarerQoL-7D (fulfilment,

relational, mental health, daily activities of the caregiver, financial, perceived support and physical health). The second part is a question that assess the level of how happy the informal caregiver felt on the CarerQoL-VAS, ranging from 0 (completely unhappy) to 10 (completely happy) ²⁷.

Higher CarerQoL-VAS scores is associated with lower SRB ($r_s = -.43$ $p < .001$). Income ($p < .05$), relationship ($p < .01$), living together ($p < .01$), health of the caregiver ($p < .001$), frequency of care ($p < .05$) and time spent at caregiving ($p < .05$) are significantly associated with the CarerQoL-VAS score ^{27,28}.

Quality of life of the informal caregiver

A score (between 0-10) was given to measure the quality of life of the informal caregivers. This is a variant of the Cantril's Self Anchoring Ladder ²⁹. Quality of life was also measured with two other questions, a variant of the first two questions from the RAND-36 questionnaire measured on a 5 points Likert Scale ²⁶. The first question measured the general quality of life of the informal caregiver (excellent – bad) and the second question measured the general quality of life now, compared to a year ago (much better – much worse).

Candidate predictors of care receivers

Quality of life of the care receiver

A score (between 0-10) was given to measure the quality of life of the care receivers. This is a variant of the Cantril's Self Anchoring Ladder ²⁹.

Daily Functioning Katz-15 (I)ADL index

The Katz-15 was used to measure the level of ADL and IADL ³⁰. The Katz-15 index measures independence of ADL on several items (bathing, dressing, toileting, transferring, eating, the use of incontinence materials, use a phone, shopping, prepare food, perform household task, travel, take medication and handle finances). The score ranged from 0 (no help) to 15 (need help). The Katz-15 is correlated with other health related well-being measurements such as SF-36 physical ($r_s = -.72$), SF-36 mental ($r_s = -.35$), SF-36 social ($r_s = -.24$), SF-36 vitality ($r_s = -.48$), EQ5-D ($r_s = -.59$), frailty index ($r_s = .27$) ³¹.

Data analysis

Baseline characteristics of the informal caregivers and the care receivers were tabulated against the presence of caregiver burden (defined as a SRB(VAS) score of ≥ 5).

Missing data rarely occur at random and a complete case analysis leads to loss of power and to biased results. Missing data in the candidate predictors were imputed by multiple imputation (MI)^{32,33}. The SPSS Statistics version 20 was used to analyse the data (IBM, New York USA). Caregivers (n=49) with no baseline data were excluded from the analysis.

First, univariate linear regression analysis was applied to examine the relationship between a predictor at T0 and the corresponding change in the outcome of caregiver burden at T12. Results were presented as Beta's with 95% confidence intervals (CI) and the *p* value. The following categorical variables were transformed to dummy variables with a code before they were analysed: the relationship with the care receiver, health of the caregiver, and quality of life of the caregiver. Selection based on univariate statistics might have resulted in an unstable prediction model, so therefore all candidate predictors were included in a multiple logistic regression analysis^{34,35}.

Second, in the model, the final predictors were identified using a backward method with multiple logistic regression. The stopping rule in a backward method can be the standard significance level for testing of hypotheses ($p=0.05$), but the Akaike Information Criterion (AIC) has been recommended^{36,37}. AIC gives a *p*-value of 0.157 for a predictor with one regression coefficient and was used as stopping rule^{37,38}. Results were reported as Odds Ratio(OR) with 95% CI and the *p* value.

Discrimination indicates how good the model classifies patients with or without caregiver burden. The area under the receiver operating characteristics curve (AUC), and the 95% CI were calculated to assess the discriminative ability of the model. Higher values of the AUC indicated better discrimination^{37,39}.

RESULTS

A total of 358 caregivers and frail older people agreed to participate. Twenty-eight caregivers (8.1%) had missing values for one or more predictors. The missing values ranged from one to eight per predictor. Characteristics of the informal caregivers are stratified by the presence or absence of caregiver burden. The mean age of the caregiver was 63.2 (SD:12.8) years, 61.3% was female and 46.8% was the husband, wife or life partner (Table 1). At baseline 48.8% (n=156) of the caregivers, and at one year follow-up 55% (n=213) of the caregivers experienced caregiver burden. The mean age of the care receivers was 78.7 (SD:8.6) years, 58.9% of the care receivers was female and the mean Katz-15 score of the care receivers was 6.5 (SD:4.4) (Table 2). Caregivers who developed caregiver burden were older, more often female and were more often living together with the care receiver. The health of the caregiver was worse, and the quality of life lower in caregivers who developed caregiver burden.

The univariate analysis showed that the general health of the caregiver, time spent at helping with personal care, the items relational problems, mental health, physical health and daily activities of the CarerQol, the CarerQol-VAS and quality of life of the caregiver and care receiver were significantly associated with caregiver burden (Tables 1 and 2).

PLEASE INSERT TABLES 1 AND 2 HERE

The multivariable logistic analysis showed that the ability to combine the care tasks with the daily activities of the caregiver (OR, 2.10; 95% CI, 1.28-3.43) was the strongest predictor. Another significant predictor in the remaining model was having relational problems with the care receiver (OR, 1.86; 95% CI, 1.13-3.07). With an increase of problems with combining care tasks with the daily activities and relational problems the degree of caregiver burden also increased.

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The model showed an AUC of 0.68 (95% CI, 0.63-0.74).

DISCUSSION

In this study, we developed a prediction model to predict caregiver burden in caregivers of frail older people during one year follow-up. The most strongest predictors were the ability to combine the care tasks with the daily activities of the caregiver and having relational problems with the care receiver. The discriminatory performance of the prediction model is moderate (AUC: 0.68).

The ability to combine care tasks with daily activities is the strongest predictor in our model and was confirmed in a prediction study which investigated caregiver burden in patients with mild dementia, although less strongly²². This predictor was also previously reported as a predictor in other patient groups like stroke, dementia and chronic illnesses^{18,20,40,41}. Having relational problems with the care receiver is not found to be a predictor in other studies. Other studies used the Caregiver Burden Inventory (CBI) to measure caregiver burden^{22,42,43}. Emotional burden is a factor of the CBI and describes the negative feeling of the caregiver towards the care receiver, compounded by the caregiver's subsequent feelings of guilt for having these socially unacceptable feelings⁴⁴. These emotional feelings can be an indication of possible relational problems. The emotional burden is a risk factor for caregiver burden^{22,42,43}. In the current study, functional ability of the care receiver was not a significant predictor which is not consistent with the literature^{17,18,22}. Also, in patients with dementia, the

functional ability of the care receiver has been shown as the strongest predictor of caregiver burden⁴¹. This indicates that the functional ability of the frail older people is not as important in predicting caregiver burden as it is in patients with dementia, stroke or epilepsy. The cognitive status of patients with dementia is an important predictor of caregiver burden in caregivers of patients with dementia, this predictor was not investigated in our study⁴¹.

In our prediction model, gender and age of the caregiver and care receiver were no significant predictors in contrast to other studies in caregivers of patients with dementia and stroke^{18,41,42}. Gender of the caregiver was found to be a predictor of caregiver burden in caregivers of patients with chronic illnesses and dementia^{20,42}. These data may suggest that age and gender of the caregiver and care receiver are only predictors of caregiver burden in patients with dementia, stroke or a chronic illness.

Our study has some limitations. First, the limited number of candidate predictors that could be included in the multiple logistic regression analysis due to the relatively small number of caregivers who experienced caregiver burden. Based on clinical practice, literature and the significance of the candidate predictors in the univariate analysis, the predictors in the multiple regression model were included. Second, this is a secondary data analysis as data was not primarily collected for the aim of this study. The caregivers of the frail older people who participated in the U-PROFIT trial were asked if they wanted to also participate²³. The caregivers who wanted to participate might already conduct more caregiver tasks and already feel more addressed as a caregiver than those who did not want to participate. The risk of caregiver burden might be higher in the group of participating caregivers, thus there may be selection bias. Third, in the U-PROFIT trial, some frail older people received an intervention²³. The caregivers may possibly inherit some things of the intervention. Finally, in this study a cutoff point of 5 was used to define caregiver burden since no clear threshold was found in the literature.

Some strengths of this study must be noted to appreciate the findings. The inclusion of caregivers with and without caregiver burden at baseline and the follow-up time of one year enables the identification of high-risk caregivers. A heterogeneous group of caregivers was included in the terms of age, relationship with the care receiver, and level of daily functioning of the care receivers measured with a Katz15 index. This provides the opportunity to investigate the caregiver burden in different age decades, relationships and Katz scores. This improves the generalizability of the study. We imputed missing data through multiple imputation which is the best method available to deal with missing values^{33,35,39}. Exclusion of all participants with missing values leads to loss of statistical power and to incorrect estimates of the predictive power of the model and specific predictors^{33,35,39}. The selection of the final predictors was performed based on multiple logistic regression, using

the backward method. The backward method is preferable compared with forward selection^{34,39}.

Since the Dutch government stimulates older people to maintain independent living, older people must increasingly depend on their caregivers^{15,16}. This may increase the risk of caregiver burden in this population. Early identification of those who are at risk is therefore important and highlights the need of a clinical prediction model.

Future research should focus on the internal validation of the prediction model and transforming the model into a clinical useful and valid instrument. To use the model with confidence, new data are needed to generalize the model. To enhance the clinical utility, the regression model should be converted into a score table, which could be used as a clinical prediction model.

In conclusion, the ability to combine the care tasks with the daily activities of the caregiver and having relational problems were found to be the most important predictors for caregiver burden in caregivers of frail older people. A clinical prediction model was developed that showed a moderate discriminatory performance with an AUC of 0.68.

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Tables

Table 1. Baseline characteristics and univariate analysis of the caregivers

	Caregivers with caregiver burden ^a N = 213	Caregivers without caregiver burden ^b N = 145	Beta	95% CI for B	P value
<i>Age caregiver, mean (SD)</i>	63.79 ± 12.61	62.47 ± 13.06	0.01	[-0.02; 0.03]	.71
<i>Female caregiver, n(%)</i>	146 (68.5)	95 (65.5)	0.03	[-0.91; 0.86]	.96
<i>Relationship, n(%)</i>					
-Husband/wife/life partner	101 (47.4)	63 (43.4)	*	*	*
-Sister (in law) / brother (in law)	6 (2.8)	5 (3.4)	0.24	[-2.52; 3.01]	.86
-Daughter (in law) / son (in law)	80 (37.6)	57 (39.3)	-0.00	[-0.73; 0.73]	1.00
-Other	26 (12.2)	20 (13.8)	-0.19	[-1.65; 1.26]	.79
<i>Living together with care receiver, n(%)</i>	119 (55.9)	73 (50.3)	0.17	[-0.61; 0.96]	.66
<i>General health of caregiver, n(%)</i>					
-Excellent - Very good	47 (22.1)	51 (35.2)	*	*	*
-Good	88 (41.3)	58 (40.0)	-0.95	[-1.90; -0.00]	.05
-Fair - Poor	78 (36.6)	37 (25.5)	0.11	[-0.64; 0.86]	.77
<i>General health year ago, n(%)</i>					
-Much better - Better	25 (11.7)	12 (8.3)	*	*	*
-Same	150 (70.4)	111 (76.6)	0.32	[-1.17; 1.81]	.67
-Worse - Much worse	38 (17.8)	22 (15.2)	-0.73	[-1.59; 0.13]	.09
<i>No time spent at caregiving, n(%)</i>					
-With household	35 (16.4)	35 (24.1)	0.70	[-0.35; 1.74]	.19
-Chores Personal care	120 (56.3)	105 (72.4)	0.98	[0.25; 1.71]	.01
-Outside activities	45 (21.1)	41 (28.3)	0.50	[-0.57; 1.57]	.35
-Assistance of other volunteers	143 (67.1)	93 (64.1)	0.03	[-0.77; 0.82]	.95
CarerQol-7D, n(%)					
<i>Fulfilment</i>			-1.07	[-3.02; 0.89]	.27
-None	19 (8.9)	7 (4.8)			
-Some	69 (32.4)	30 (20.7)			
- A lot of	125 (58.7)	108 (74.5)			
<i>Relational problems</i>			1.35	[0.46; 2.24]	.00
-None	118 (55.4)	110 (75.9)			
-Some	79 (37.1)	31 (21.4)			
-A lot of	16 (7.5)	5 (3.4)			
<i>Mental health problems</i>			1.04	[0.21; 1.87]	.02
-None	101 (47.4)	93 (64.1)			
-Some	90 (42.3)	44 (30.3)			
-A lot of	22 (10.3)	8 (5.5)			

<i>Physical health</i>			1.06	[0.23; 1.87]	.01
-None	85 (39.9)	82 (56.6)			
-Some	111 (52.1)	56 (38.6)			
-A lot of	17 (8.0)	8 (5.5)			
<i>Problems daily activities</i>			1.33	[0.57; 2.08]	.00
-None	111 (52.1)	100 (69.0)			
-Some	85 (39.9)	37 (25.5)			
-A lot of	18 (8.5)	9 (6.2)			
<i>Financial problems</i>			0.86	[-0.70; 2.41]	.27
-None	186 (87.3)	131 (90.3)			
-Some	21 (9.9)	9 (6.2)			
-A lot of	6 (2.8)	5 (3.4)			
<i>Perceived support</i>			-0.43	[-1.14; 0.28]	.22
-None	116 (54.4)	66 (45.5)			
-Some	70 (32.9)	56 (38.6)			
-A lot of	27 (12.7)	24 (16.6)			
<i>CarerQoL-VAS , mean (SD)</i>	6.89 ± 1.56	7.27 ± 1.65	-0.30	[-0.70; 0.10]	.13
<i>CarerQoL-VAS with help, mean(SD)</i>	5.05 ± 2.54	4.63 ± 2.79	0.19	[0.05; 0.32]	.01
<i>General quality of life, n(%)</i>					
-Excellent - Very good	57 (26.8)	63 (43.4)	*	*	*
-Good	96 (45.1)	62 (42.8)	-0.87	[-1.72; -0.02]	.04
-Fair - Poor	61 (28.6)	20 (13.8)	-0.12	[-0.86; 0.62]	.75
<i>Score of quality of life, mean (SD)</i>	7.54 ± 1.13	7.09 ± 1.27	-0.27	[-0.55; 0.00]	.05
<i>General quality of life a year ago, n(%)</i>					
-Much better - Better	27 (12.7)	24 (16.6)	*	*	*
-Same	143 (67.1)	97 (66.9)	-0.57	[-1.76; 0.63]	.35
-Worse - Much worse	44 (20.7)	25 (17.2)	-0.03	[-1.12; 1.07]	.96

SRB (VAS): Self-Rated Burden Visual Analogue Scale; CarerQoL-7D: Care-related Quality of life; CarerQoL-VAS : Care-related Quality of life Visual Analogue Scale

^a SRB ≥ 5 with caregiver burden

^b SRB < 5 without caregiver burden

* Reference category

Table 2. Baseline characteristics and univariate analysis of the care receivers

		Beta	95% CI for B	P value
<i>Age care receiver , mean (SD)</i>	78.68 ± 8.6	0.02	[-0.02; 0.06]	.38
<i>Female care receiver , n(%)</i>	211 (58.9)	-0.34	[-1.04; 0.35]	.33
<i>General quality of life, mean (SD)</i>	6.41 ± 2.0	-0.07	[-0.34; 0.21]	.62
<i>Katz15 score, mean (SD)</i>	6.49 ± 4.4	0.07	[-0.08; 0.22]	.34

Table 3. Multivariable logistic regression analysis of selected predictors of caregiver burden

	OR	95% CI for OR	P value
<i>Age caregiver</i>	1.01	[0.99 ; 1.03]	.32
<i>Gender caregiver</i>	1.27	[0.76 ; 2.12]	.36
<i>CarerQol-7D</i>			
- Problems daily activities	2.10	[1.28 ; 3.43]	.00
- relational problems	1.86	[1.13 ; 3.07]	.02
<i>Score of quality of life cg</i>	1.06	[0.94 ; 1.18]	.34
<i>Time spent personal care</i>	1.48	[0.90 ; 2.42]	.12
<i>Katz-15 score</i>	1.05	[0.99 ; 1.10]	.09