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Published in:
Aging & Mental Health

Document version:
Publisher's PDF, also known as Version of record

DOI:
[10.1080/13607863.2018.1531374](https://doi.org/10.1080/13607863.2018.1531374)

Publication date:
2019

[Link to publication](#)

Citation for published version (APA):
Jütten, L. H., Mark, R. E., & Sitskoorn, M. M. (2019). Predicting self-esteem in informal caregivers of people with dementia: Modifiable and non-modifiable factors. *Aging & Mental Health*.
<https://doi.org/10.1080/13607863.2018.1531374>

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To cite this article: Linda H. Jütten, Ruth E. Mark & Margriet M. Sitskoorn (2018): Predicting self-esteem in informal caregivers of people with dementia: Modifiable and non-modifiable factors, *Aging & Mental Health*, DOI: [10.1080/13607863.2018.1531374](https://doi.org/10.1080/13607863.2018.1531374)

To link to this article: <https://doi.org/10.1080/13607863.2018.1531374>



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Predicting self-esteem in informal caregivers of people with dementia: Modifiable and non-modifiable factors

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ABSTRACT

While informal caregivers often feel burdened by the care for a person with dementia, they can also experience positive consequences due to caregiving; caregiver gains. One of these, relatively overlooked, caregiver gains is heightened self-esteem. We assessed the predictive ability of non-modifiable (caregiver sociodemographic- and dementia related-) and modifiable (psychological-) factors for caregiver self-esteem). A cross-sectional study in which 201 caregivers, who spent at least eight hours a week on caring for a community-residing person with dementia, completed a semi-structured interview and five questionnaires. One two-block (1: non-modifiable-; 2: modifiable variables) hierarchic multiple regression analysis was used to assess which variables predicted self-esteem. None of the non-modifiable variables significantly predicted self-esteem. Regarding the modifiable variables, depression and relationship quality with the person with dementia significantly predicted self-esteem (adjusted $R^2 = .460$, $\beta = -.207$, $p = .015$ and $\beta = .632$, $p < .001$ respectively). Caregivers who experience a better relationship quality with the person with dementia, and fewer depression symptoms, experience a higher level of self-esteem. Interventions focused on heightening self-esteem should strive to optimize these factors to enhance the lives of informal dementia caregivers.

ARTICLE HISTORY

Received 25 October 2017
Accepted 25 September 2018

KEYWORDS

Burden; dementia; gains; informal caregiver; relationship quality; self-esteem

Introduction


The prevalence of dementia is rising, with an estimated number of 131.5 million people living with dementia in 2050 worldwide (Prince et al., 2015). Most people with dementia live at home and are dependent on informal caregivers, typically unpaid spouses, children, or other relatives, for most of their daily care. The literature has primarily focused on the negative consequences of informal caregiving: caregivers are thought to be more depressed and anxious than non-caregivers. In addition, they can experience caregiver burden, a multidimensional response to the various stressors associated with the caregiving experience (Etters, Goodall, & Harrison, 2008). However, some caregivers (also) experience positive consequences of caregiving, which a growing body of literature is beginning to acknowledge. These positive consequences are often called caregiver gains. Focus on this positive side of caregiving is warranted because these aspects might help buffer against caregiver burden (Cohen, Colantonio, & Vernich, 2002), and negative affect (Rapp & Chao, 2000) and in turn reduce the likelihood that the person with dementia will be institutionalised (Cohen, Gold, Shulman, & Zuccherro, 1994; Mausbach et al., 2004). Furthermore, focussing on the positive side of caregiving could lead to a more positive caregiving experience overall (Fredrickson, 2001), and needs to be considered in order to obtain a more comprehensive view of caregiving (Zarit, 2012). The lack of information on the positive consequences (and the general

focus on the negative), distorts how the caregiving experience is perceived and as such limits research in the caregiver-research field (Louderback, 2000).

To date there is no single, accepted definition for the concept of caregiver gains (Carbonneau, Caron, & Desrosiers, 2010). Gains have been primarily operationalized in terms of caregiver self-report, and have included satisfaction with the caregiver role, the feeling of being appreciated or needed, spirituality, rewards, finding meaning in life, enrichment events in daily life, quality of the caregiver/person with dementia relationship, feelings of accomplishments, well-being, and resilience (Carbonneau et al., 2010; Lloyd, Patterson, & Muers, 2016; Stansfeld et al., 2017). Due to these differences in conceptualisation, gains have been operationalized differently across studies as well. Gains have been subjectively measured using self-report questionnaires assessing specific aspects of the concept (Stansfeld et al., 2017) or via open-ended questions in interviews.

Self-esteem is the extent to which one values, approves or likes oneself (Robinson, Shaver, & Wrightsman, 2013), and is, to date, a relatively overlooked variable in informal caregiver research. Self-esteem has been found to positively correlate with well-being and negatively correlate with caregiver burden (Chappell & Reid, 2002; Lethin et al., 2017), but has primarily functioned as a moderator or predictor variable in caregiver research (Chappell & Reid, 2002; Lethin et al., 2017; Mroz et al., 2017) instead of the

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 Supplemental data for this article can be accessed [here](#).

outcome variable of interest. However, since self-esteem predicts success and well-being (Orth & Robins, 2014), and given that caregiving can affect the way caregivers value themselves (Tuomola, Soon, Fisher, & Yap, 2016), it is important to pay more attention to self-esteem in the caregiver literature. In order to explore this aspect in more detail and broaden the definition of caregiver gains, the current study focused on self-esteem as a measure of caregiver gains.

Several studies have examined predictive factors for gains, but the results to date are inconclusive. This ambiguity is likely due to differences in how gains have been conceptualized and measured, differences in study populations, and differences in which predictors have been included in the analyses (Kramer, 1997). Identified caregiver psychosocial predictors so far include more socio-emotional support (Cheng, Lam, Kwok, Ng, & Fung, 2013; Shirai, Silverberg Koerner, & Baete Kenyon, 2009); less experienced (subjective) burden (de Labra et al., 2015); better mental well-being of the caregiver (Liew et al., 2010); a higher quality pre-morbid relationship with the person with dementia (Kramer, 1993); and a higher intrinsic motivation for caregiving (Quinn, Clare, McGuinness, & Woods, 2012). In addition, some caregiver sociodemographic and care-related predictors have been identified, including having a consanguinity relationship with the person with dementia (de Labra et al., 2015), and more hours spent on care (Quinn et al., 2012). However, most of these predictors have been explored using only one specific aspect of gains, and some studies have relied on correlational (univariate) methods to investigate which factors are associated with gains (e.g. Grover, Nehra, Malhotra, & Kate, 2017), and univariate analyses do not allow for identification of which predictors are most important. It remains unknown whether there are psychosocial (modifiable) predictors which predict gains irrespective of sociodemographic (non-modifiable) characteristics. Conceptualizing factors as modifiable and non-modifiable is important from a clinical and intervention perspective, because modifiable risk factors are amenable to interventions (Bahr & Holme, 2003). If modifiable predictors for self-esteem are known, interventions could target these to improve the lives of the caregivers, and indirectly the lives of the people with dementia (Brodaty & Donkin, 2009). Although non-modifiable factors may not be useful as targets for interventions, these are important in order to identify caregivers who experience fewer (or more) gains (Cameron, 2010).

The present study aimed to identify (modifiable) psychological variables predicting caregiver gains (operationalized as self-esteem) while controlling for (non-modifiable) socio-demographic- and dementia-related variables (time since diagnosis, and the time spent on caregiving by the caregiver). We hypothesized that more social support and less burden would predict more self-esteem. We also tested the predictive ability of depression, anxiety, and relationship quality with the person with dementia for caregiver gains. The modifiable variables depression and anxiety were chosen because these are the two most common complaints of caregivers (Cooper, Balamurali, & Livingston, 2007); relationship quality was selected because this is found to have a significant impact on caregivers' well-being (Quinn, Clare, & Woods, 2009), caregivers' physical

and mental health (Fauth et al., 2012), and on the symptoms of the person with dementia (Norton et al., 2009).

Design and methods

Study design

The current cross-sectional study used the baseline data of a larger, ongoing study. The protocol for the entire study (Jütten et al., 2017), explains the method in greater detail.

Participants

All participants were adult informal caregivers who provided at least eight hours per week on care for a relative, spouse, or friend with dementia who lived at home (not institutionalized). They were not prohibited from having a case manager (which is considered to be usual care in the Netherlands). The participants were recruited from de Wever in Tilburg, the Netherlands, an organization for eldercare; elderly federations; Alzheimer Nederland; case managers; centers for daytime activities for people with dementia; private and professional networks of the researchers, and via social media.

Measures

A more detailed description of all measures is given in [Supplementary Text S1](#).

Dependent variable

Self-esteem was assessed using the Caregiver Reaction Assessment – Dutch (CRA-D) (Nijboer, Triemstra, Tempelaar, Sanderman, & Van Den Bos, 1999), subscale self-esteem.

Non-modifiable predictors

Caregiver sociodemographic factors. The caregiver sociodemographic factors were age (in years), sex, level of education according to Verhage (recoded into low, medium, and high) (Verhage, 1964), the type of relationship with the person with dementia (spouse/child/other), and whether or not the caregiver and the person with dementia lived together.

Dementia-related factors. The dementia-related factors were the time since diagnosis (in years) and the time spent on providing care a week (in hours).

Modifiable predictors

Social support was measured using the Dutch version of the Inventory for Social Reliance (ISR) – qualitative part (van Dam-Baggen & Kraaimaat, 1992); relationship quality was assessed using the Relationship Quality Index (RQI) (Norton, 1983); depression and anxiety were measured using the Hospital Anxiety and Depression Scale (HADS), subscale Depression and Anxiety respectively (Zigmond & Snaith, 1983); and caregiver burden was assessed using the Caregiver Reaction Assessment – Dutch (CRA-D) (Nijboer et al., 1999), subscales Financial Problems, Impact of caregiving on disrupted schedule, Lack of family support, and Health problems.

Table 1. Caregiver characteristics (non-modifiable factors), presented as mean \pm SD; or n, %.

Caregiver sociodemographic variables (n = 201)		
Age		60.8 \pm 12.0
Sex, %male		43, 21.4%
Level of education ^a	Low	30, 14.9%
	Medium	72, 35.8%
	High	99, 49.3%
Relationship with the person with dementia	Spouse	82, 41.0%
	Child	90, 45.0%
	Other	29, 14.0%
Cohabiting with the person with dementia, %yes		78, 38.8%
Characteristics of person with dementia - and dementia related variables		
Age		78.6 \pm 8.3
Sex, %male		87, 43.3%
Dementia diagnosis	AD	116, 57.7%
	VaD	35, 17.4%
	PD	4, 2.0%
	Other	15, 7.5%
	NDD	31, 15.4%
Hours providing care a week		56.0 \pm 63.1
Time since diagnosis in years		3.1 \pm 2.5

Note. AD = Alzheimer's Disease; VaD = Vascular Dementia; PD = Dementia associated with Parkinson's Disease; NDD = No differential diagnosis.

^aEducational level, according to Verhage (Verhage, 1964); recoded into low (1–4); medium (5); and high (6–7).

Procedure

Potential participants received oral and written information about the study from case managers, nurses, and supervisors at day-time activity centers, or only written information on social media. The participants were invited to contact the researchers (LJ) by phone or e-mail if they had questions and to receive more information about the study. If they were interested in participating, the appointment for the semi-structured interview was scheduled and the questionnaires were sent. The interviews consisted of questions about sociodemographic information and the dementia-related information, and were conducted by trained neuropsychologists. During the interviews the participants received help with the questionnaires if needed. The interviews took place either at Tilburg University or at the participants' homes; depending on the participants' preference. Written informed consent was obtained from the caregivers (the people with dementia did not take part in the study) and the study protocol has been approved by the local ethics committees.

Power analysis

The sample size needed was calculated with G*Power. Based on an alpha level of .02, a power of .80, and 17 predictors, at least 175 participants were needed to detect medium ($f^2 = .15$) effects.

Statistical analyses

Statistical analyses were performed using SPSS Statistics 22 (SPSS Inc, 2013). Descriptive statistics and frequencies were used to describe the study sample (see Table 1).

One hierarchical multiple regression analysis, consisting of 2 blocks was performed: Block 1: (non-modifiable) socio-demographic- and dementia related variables; Block 2: (modifiable) caregiver psychological variables. Within the blocks, the forced entry method was used to reduce the influence of random variation in the data and increase the

replicability of the results (Field, 2009). To adjust for multiple comparisons, the alpha level was restricted to .02.

Results

Two hundred and one caregivers completed the questionnaires and semi-structured interviews. The mean age of the caregivers was 61; the majority was female (87%), attained a high level of education, and cared for their spouse or parent. The mean age of the people with dementia was 79 and most (58%) were diagnosed with Alzheimer's disease. An overview of the sociodemographic characteristics, and scores on dependent and predictor variables can be found in Table 1 and Supplementary Table S1 respectively.

Preliminary analyses were conducted to ensure no violations of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. The sociodemographic variable 'cohabiting with the care receiver' was dropped from the regression analysis because the correlation with the variable 'type of relationship with the care receiver' was too high ($\chi^2(2) = 171,270$, $p < .001$), causing multicollinearity.

The results of the regression analysis are given in Table 2. In Model 1, the non-modifiable (sociodemographic and dementia-related-) variables were entered. None of the variables were found to be significant predictors, and the model as a whole only explained 5% of the variance in caregiver self-esteem. In Model 2, the modifiable variables were entered. This model explained 51% of the variance, $F(16, 162) = 10.487$, $p < .001$. In this model, the variables relationship quality with the person with dementia and depression were statistically significant ($\beta = .621$, $p < .001$, and $\beta = -.207$, $p = .015$ respectively).

Discussion

This study explored the predictive ability of non-modifiable (caregiver demographic- and dementia-related-) and modifiable (caregiver psychological-) factors for caregiver gains, operationalized as caregiver self-esteem.

None of the non-modifiable variables significantly predicted self-esteem. Regarding the modifiable predictors, relationship quality and depression symptoms were found to be predictive of self-esteem. The finding regarding relationship quality is in line with a systematic review (Quinn et al., 2009), which found that the caregiver's perception of current relationship quality may have an impact not only on both the caregivers' and person with dementia's well-being, but also on the caregivers' ability to continue caregiving. In addition, relationship quality has been found to predict caregiving satisfaction (Kramer, 1993; Sánchez-Izquierdo, Prieto-Ursúa, & Caperos, 2015) in informal dementia caregivers. Furthermore, in general, rewarding aspects of relationships are found to be positively related to self-esteem (Voss, Markiewicz, & Doyle, 1999), which we used as measure of caregiver gains. The finding regarding depression is in line with a previous study (Cohen et al., 2002), which found that positive feelings about caring were associated with lower depression scores. Beyond the scope of caregiving research, a meta-analysis (Sowislo & Orth, 2013), also found that depression and self-esteem are strongly related. The direction of this relationship, i.e.

Table 2. Hierarchical multiple linear regression analysis for variables predicting caregiver self-esteem ($n = 201$).

Predictor	Model 1			Model 2		
	B	SE B	β	B	SE B	β
Constant	3.33	0.35		2.14	0.40	
Age	0.01	0.01	.158	0.01	0.01	.082
Sex (0 = female, 1 = male)	0.11	0.12	.076	0.07	0.07	.048
Level of education ^a - Low	-0.02	0.14	-.015	-0.12	0.11	-.074
Level of education ^a - High	0.02	0.10	.014	-0.07	0.07	-.060
Relationship with person with dementia - Spouse	-0.28	0.18	-.240	-0.18	0.14	-.155
Relationship with person with dementia - Child	0.11	0.14	.092	-0.03	0.10	-.027
Hours providing care a week	0.01	0.01	.022	0.01	0.01	.035
Time since diagnosis	-0.01	0.02	-.012	0.01	0.01	.030
Social support				0.01	0.01	.033
Relationship quality				0.04	0.01	.621**
Depression				-0.03	0.01	-.207*
Anxiety				0.01	0.01	.043
Burden - Financial problems				-0.02	0.05	-.028
Burden - Impact of caregiving on disrupted schedule				0.07	0.06	.102
Burden - Lack of family support				0.05	0.05	.067
Burden - Health problems				-0.05	0.07	-.074
Total R ²	0.05			0.51		
Adjusted R ²	0.01			0.46		
Total F	1.11			10.49**		
ΔR^2				0.46**		
ΔF				18.93**		

^aNote. Educational level, according to Verhage (Verhage, 1964); recoded into low (1–4); medium (5); and high (6–7); medium was the reference category. The variable ‘cohabiting with the person with dementia’ was dropped from the analysis, because the correlation with the variable ‘Relationship with person with dementia’ was too high ($p < .001$), causing multicollinearity.

* $p < .02$; ** $p < .001$.

whether depression leads to low self-esteem, or vice versa, is not yet known.

In contradiction with our hypothesis and previous research (e.g. de Labra et al., 2015), that gains would be predicted by burden, none of the subscales predict self-esteem. These contradictory findings can be explained by the fact that we used different conceptualizations of gains than de Labra et al (2015). De Labra et al. (2015) operationalized caregiver gains as caregiver satisfaction, and measured it with the Caregiver Satisfaction Scale. While this questionnaire does include one item related to caregiver self-esteem, this scale is very different from our operationalisation of caregiver gains. Another explanation lies in the measures used for burden. De Labra et al. (2015) used one total score (from the Zarit Burden Interview) to measure burden, while we focused on the separate subscales of the CRA. Future research could focus on exploring these different conceptualisations and operationalisations of burden and gains and the associated predictors for both.

Contrary to our hypothesis, and to other studies which found that social support was highly correlated (Grover et al., 2017) and an important predictor for gains (Cheng et al., 2013; Shirai et al., 2009) we did not find that more social support predicted self-esteem. Explanations for these contradictory findings lie in the measures used for either social support and/or gains. We measured general social support, while Shirai et al. (2009) specifically identified partner social support (not from friends) as positive predictor. Shirai et al. (2009) suggested that family members are more likely to share caregiving standards and values with the caregivers than friends, which helps them to provide meaningful social support. This gives caregivers confidence and a sense of appreciation in their caregiver role, which leads to greater feelings of gain. Conversely, contact with friends may also remind the caregiver of missed and limited social opportunities due to their caregiver role (Shirai

et al., 2009). However, Cheng et al. (2013) did find that aspects of general social support (network size, and positive social exchanges) significantly predicted gains. Cheng et al. (2013) measured gains using the Positive Aspects of Caregiving survey, which focusses on self-affirmation and outlook on life, which are different from our operationalisations of gains. Future gains-research should therefore consider who provides the support, and which aspect of gains to measure.

There were some limitations. The study was cross sectional in design making it impossible to talk about cause-effect relationships. Secondly, the dependent variable was measured using the CRA-D. While this is a validated questionnaire, it is not specifically designed to measure the broad concept of caregiver gains, but to measure a certain aspect of it. As a consequence, our results cannot be compared with studies measuring other aspects of gains without reservations.

Implications and conclusion

A more comprehensive definition for gains encompassing multiple aspects is needed and future research into gains should include a number of different aspects of gains. Ideally, future research should look into developing a questionnaire encompassing multiple aspects of gains to allow comparisons across studies and assist in replication of findings. It is likely that different aspects of gains have different predictors. Clinical practice with informal dementia caregivers should however be alerted to the fact that caregivers can experience gains and not only focus on the negative consequences.

In conclusion, caregiver gain is an important, and still relatively under-researched concept. A positive approach is warranted because not all caregivers experience negative consequences and focussing on this positive side may lead

to a more affirmative experience. Our results suggest that a better quality of the relationship with the person with dementia and fewer depression symptoms are predictive of self-esteem, irrespective of sociodemographic characteristics. Interventions for caregivers could try to focus on enhancing relationship quality and on reducing symptoms of depression. This may lead to a higher level of self-esteem which could ultimately improve the lives of both the caregiver and the person with dementia.

Acknowledgments

We thank the Alzheimer cafes, case managers, supervisors at day-time activity centres and De Wever in Tilburg for their efforts in helping us to recruit participants. We would especially like to thank all the informal caregivers who participated in this study for their time.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the program Memorabel, of The Netherlands Organisation for Health Research and Development (ZonMw), part of The Netherlands Organisation for Scientific Research (NWO); and Alzheimer Nederland (project number: 733050608). However, solely the authors are responsible for the design and conduct of this study, study analyses, interpreting, drafting and editing of this article.

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