Am J of Geriatric Psychiatry ■ : ■ (2019) ■ ■ - ■ ■



Available online at www.sciencedirect.com

ScienceDirect

journal homepage: www.ajgponline.org



Regular Research Article

Influence of Positive and Negative Dimensions of Dementia Caregiving on Caregiver Well-Being and Satisfaction With Life: Findings From the IDEAL Study

Catherine Quinn, Ph.D., Sharon M. Nelis, Ph.D, Anthony Martyr, Ph.D., Christina Victor, Ph.D., Robin G. Morris, Ph.D., Linda Clare, Sc.D.; on behalf of the IDEAL study team

ARTICLE INFO

Article history: Received December, 3 2018 Revised February, 4 2019 Accepted February, 6 2019

Key Words:
Competence
gains
stress
role-captivity
positive aspects of caregiving
quality of life

ABSTRACT

Objective: The aim of this study was to identify the potential impact of positive and negative dimensions of caregiving on caregiver well-being and satisfaction with life (SwL). Methods: This study used time-point one data from the Improving the experience of Dementia and Enhancing Active Life (also known as IDEAL)cohort study that involved 1,283 informal caregivers of people in the mild-to-moderate stages of dementia recruited from 29 sites within Great Britain. Multivariate linear regression modeling was used to investigate the associations between positive dimensions of caregiving (measured by caregiving competence and perceptions of positive aspects of caregiving), negative dimensions of caregiving (measured by caregiving stress and role captivity), and caregiver well-being and SwL. Results: Lower well-being was associated with low caregiving competence (-13.77; 95%) confidence interval [CI]:-16.67, -10.87), perceiving fewer positive aspects of caregiving (-7.67, 95% CI: -10.26, -5.07), bigh caregiving stress (-24.45; 95% CI:-26.94, -21.96), and bigh role captivity (-15.61; 95% CI:-18.33, -12.89). Lower SwL was associated with low caregiving competence (-4.61; 95% CI: -5.57, -3.66), perceiving fewer positive aspects of caregiving (-3.09; 95% CI:-3.94, -2.25), high caregiving stress (-7.88; 95% CI:-8.71, -7.06), and high role captivity (-6.41; 95% CI:-7.27, -5.54). When

From the Centre of Applied Dementia Studies (CQ), University of Bradford, Faculty of Health Studies, Bradford, United Kingdom; Centre for Research in Ageing and Cognitive Health (REACH) (CQ, SMN, AM, LC), University of Exeter Medical School and College of Life and Environmental Sciences, St Luke's Campus, Exeter, United Kingdom; Department of Clinical Sciences (CV), College of Health and Life Sciences, Brunel University London, Uxbridge, United Kingdom; and the King's College London Institute of Psychiatry, Psychology and Neuroscience (RGM), London. Send correspondence and reprint requests to Catherine Quinn, Ph.D., Centre of Applied Dementia Studies, Faculty of Health Studies, University of Bradford, Bradford, United Kingdom, BD7 1DP. e-mail: c.quinn1@bradford.ac.uk

© 2019 The Authors. Published by Elsevier Inc. on behalf of American Association for Geriatric Psychiatry. This is an open access article under the CC BY license. (http://creativecommons.org/licenses/by/4.0/) https://doi.org/10.1016/j.jagp.2019.02.005

Positive and Negative Dimensions of Caregiving

these four measures were combined within the same model, only positive aspects of caregiving and caregiving stress retained independent associations with well-being and SwL. Conclusion: Both positive and negative dimensions of caregiving were associated with caregiver well-being and SwL. Psychological therapies and interventions need to consider not only the negative aspects of caregiving but also positive caregiving experiences and their implications for caregiver well-being and SwL. (Am J Geriatr Psychiatry 2019;

INTRODUCTION

here is an increasing recognition, in both policy and practice, of the need for better support for informal caregivers of people with dementia.^{1,2} Understanding the factors that can influence the wellbeing of caregivers is important for the development of effective support. Caregiving can be both a rewarding and a stressful experience, yet caregiving research has tended to focus on the negative outcomes of caregiving. It is well recognized that caregiving can have a detrimental impact on caregivers' health and wellbeing;³ however, caregivers can also experience positive aspects of providing care, which may have a beneficial influence on their well-being.⁴ Research exploring the influences of positive and negative dimensions of caregiving on caregiver well-being has been guided by conceptual models, such as the Stress Process Model,⁵ which identify specific outcomes of caregiving such as depression or anxiety. Therefore, the majority of research on dementia caregiving has focused on specific domains of well-being, such as depression or burden, rather than using a more global measure of well-being.⁶ There are benefits of using global measures of well-being as outcomes in caregiving research. They allow for the simultaneous exploration of multiple dimensions of well-being and can provide valuable insight into caregivers' overall wellbeing, allowing for comparisons with other groups of caregivers and noncaregivers. Well-being is a multidimensional concept containing both cognitive and psychological components. It has been proposed that a related concept, satisfaction with life (SwL), relates to the cognitive evaluative aspects of well-being.8 This article will explore how positive and negative dimensions of caregiving are linked to both caregiver well-being and SwL.

Many factors are thought to influence the wellbeing of caregivers.⁵ Research on stress and adaption indicates that specifically in challenging circumstances both positive and negative psychological states can co-occur; thus, positive emotions can have a role in how people respond and adjust to such experiences. In caregiving, it is proposed that the positive dimensions of caregiving can encompass identifying positive aspects of providing care, and also the experience of caregiving self-efficacy or feelings of competence in their role. 10 Identifying positive aspects of caregiving can have a positive influence on the caregiving experience. 11,12 Several theoretical models have been developed that incorporate both positive or negative responses to a stressful event, for example, the revised stress and coping model. Based on two-factor theories of psychological well-being, twofactor models of caregiving propose that positive and negative dimensions of well-being can have different predictors.¹³ The two-factor model conceived by Kramer⁴ proposed that appraisals of role gain results in positive outcomes and appraisals of role strain results in negative outcomes. Similarly, a two-factor model developed by Lawton et al.¹³ indicated that for spousal caregivers burden was only associated with depression, and conversely satisfaction was only associated with positive affect. However, this association was not apparent for adult-child caregivers. These findings provide preliminary evidence that, when considered together, positive and negative dimensions of caregiving may have differential influences on the caregiving experience.

Relatively few studies have explored the associations of positive and negative dimensions of caregiving with caregiver well-being and SwL. Those studies that have been conducted have tended to focus on caregiver burden, with few exploring other negative aspects of the caregiving experience, in particular, caregiving stress and role captivity. Caregiving stress encompasses both the psychological and emotional reactions to the demands of caregiving, whereas role captivity concerns caregivers' feelings of being

Quinn et al.

trapped in the caregiving role.⁵ Limited studies have explored the association of caregiver stress with SwL and well-being, indicating that higher stress is associated with lower SwL¹⁵ and lower well-being.⁸ In terms of the positive dimensions of caregiving, some studies suggest that higher perceived positive aspects of caregiving are associated with better SwL^{16,17} and well-being, ^{18,19} although others did not find these associations.^{20,21} To our knowledge, no study has explored the associations of caregiver competence or role captivity with well-being and SwL.

Building on the findings of the two-factor models, this study seeks to explore the association between positive and negative dimensions of caregiving on caregiver well-being and SwL. Although there is preliminary evidence that both positive and negative dimensions of caregiving can influence caregiver well-being and SwL, there is little evidence regardingthe combined influence of these factors when considered together. The aim of this study is to identify the potential impact of positive and negative dimensions of caregiving on the well-being and SwL of caregivers of people with mild-to-moderate dementia.

METHODS

Design

This study useddata from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) longitudinal cohort study.²² The participants in the IDEAL study at baseline are people with mild-to-moderate dementia and their informal caregivers, when available. This study uses data from time-point oneof the IDEAL study collected between July 2014 and August 2016. The IDEAL study was approved by the Wales 5 National Health Service Research Ethics Committee (reference 13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014–11684). The IDEAL study is registered with UKCRN, registration number 16593.

Participants

Informal caregivers of people with dementia were approached to participate in the study if the person they cared for with dementia consented to participate. 'Informal caregiver' was defined as the primary person

who provides practical or emotional unpaid support, usually a family member. To enter the study, people with dementia had to be residing in the community, have a diagnosis of dementia (any sub-type), and have a Mini-Mental State Examination²³ score of 15 or above, indicating that they were in the mild-to-moderate stages of dementia. The exclusion criteria for people with dementia were a comorbid terminal illness, inability to provide informed consent, and any potential risks to researchers conducting home visits. There were no additional exclusion criteria for caregivers.

Measures

To address the aims of the study, a specific sub-set of measures from the IDEAL study was used. Details of the measures included in the IDEAL study are reported in the protocol.²²

Background information

Data were collected on caregivers' age, gender, kin-relationship to the person with dementia, and hours spent caregiving per week. For the person with dementia, we collected information on age, gender, and dementia diagnosis, and the Mini-Mental State Examination score was recorded.

Positive dimensions of caregiving

Caregiving competence was measured using the 3-item Caregiving Competence scale²⁴ (example item: How often do you feel confident that you are meeting the needs of your relative/friend?). Items are rated on a 4-point Likert scale ranging from one (never) to four (all of the time), with higher scores indicating greater competence in their role.

Perceptions of positive aspects of caregiving were measured using the 9-item Positive Aspects of Caregiving scale²⁵ (example item: Providing help to my relative/friend has made me feel strong and confident). Items are rated on a 5-point Likert scale ranging from one (disagree a lot) to five (agree a lot), with a higher score indicating more positive appraisals of caregiving.

Negative dimensions of caregiving

Caregiving stress was measured using the Relative Stress scale¹⁴ (example item: Do you ever feel

Positive and Negative Dimensions of Caregiving

that you can no longer cope with the situation?). The 15-items are rated on a 5-point Likert scale ranging from zero (not at all) to four (always/considerably), with a higher score indicating greater stress.

Role captivity was measured using the 3-item Role Captivity scale⁵ (example item: How much do you wish you could just run away?). Items are rated on a 4-point Likert scale ranging from one (never) to four (all of the time), with higher scores indicating greater role captivity.

Outcome measures

Well-being was measured using the 5-item World Health Organization-Five Well-Being Index²⁶ (example item: I have felt cheerful and in good spirits). Items are rated on a 6-point scale from zero (at no time) to five (all of the time), which are then summed and transformed into a percentage score. Higher scores indicate better well-being. The measure has demonstrated good reliability in a sample of caregivers.²⁷

SwL was measured using the 5-item Satisfaction with Life scale²⁸ (example item: In most ways my life is close to my ideal). Items are rated on a 7-point scale from one (strongly disagree) to seven (strongly agree), with a higher score indicating better SwL. The scale has demonstrated good reliability in a sample of caregivers of people with dementia.²⁹

Procedure

Researchers from clinical research networks were responsible for participant recruitment and assessment. Participants were identified from 29 National Health Service sites within Great Britain. Participants were recruited from a variety of sources including memory services and other specialist clinics. Participants were also recruited from Join Dementia Research (a United Kingdom based online service that enables volunteers, including people with dementia, to register their interest in taking part in research). Potential participants were contacted regardingthe study, and a researcher then visited those who expressed interest in participating. The researcher completed the eligibility checks and obtained informed consent. The caregivers self-completed their assessments but could seek help from the researcher if necessary. All the time-point one assessments were completed during three visits.

Analyses

The measures of caregiving competence, perceptions of positive aspects of caregiving, caregiving stress, and role captivitywere skewed and when the distributions deviated from normality it was decided that, for the purposes of the analysis, these measures should be converted into tertiles. By converting the measures into tertiles, this allowed for comparison between those with high, moderate, and low scores on all of the caregiver measures. Correlations were conducted to explore the associations between wellbeing and SwL. Multivariate linear regression modeling was used to investigate differences in well-being and SwL through a series of steps. First, individual models were tested for each of the measures to explore whether the measures had individual associations with well-being and SwL. Second, these models were then adjusted for caregivers' age, gender, kinrelationship, hours per week providing care, and specific diagnosis of the person with dementia. Third, as the results indicated that the measures had independent associations with well-being and SwL, additional multivariate models were applied to investigate whether the measures retained these independent associations when the measures were considered together. As the measures were grouped under positive and negative dimensions of caregiving, the associations of each group of measures with wellbeing and SwL were explored first. The measures of positive dimensions of caregiving (caregiving competence and positive aspects of caregiving) were included together in one adjusted model, with the measures of negative dimensions of caregiving (caregiving stress and role captivity) included in a separate adjusted model. Finally, all the measures were included in a single combined model. This study used the IDEAL time-point one dataset (v2). For each model, we also conducted the Wald test, which examined whether the whole measure (rather than individual tertials) were associated with well-being and SwL. Analyses were conducted in StataSE 15 (Stata-Corp, College Station, Tex, United States).

RESULTS

Demographic information regardingthe participants in the study is provided in Table 1, and

TABLE 1. Characteristics of the Caregivers and the Participants With Dementia

Demographic Information	N (%)
Caregivers	N=1,283
Gender (female)	881 (68.7%)
Age (years):<65	369 (28.8%)
65-69	208 (16.2%)
70-74	267 (20.8%)
75-79	223 (17.4%)
80+	216 (16.8%)
Kin-relationship: Spouse/partner	1,039 (81%)
Other family/friend	244 (19%)
Education: ^a No qualification	265 (21.5%)
School leaving certificate at age 16	274 (22.2%)
School leaving certificate at age 18	374 (30.4%)
University/College	319 (25.9%)
Hours of care: ^b < 1 hour	232 (18.8%)
1-10 hours	499 (40.4%)
10+ hours	415 (33.6%)
Other responses	89 (7.2%)
Person with dementia	N=1,283
Gender (female)	528 (41.2%)
Age (years):<65	103 (8%)
65-69	160 (12.5%)
70-74	232 (18.1%)
75-79	306 (23.9%)
80+	482 (37.6%)
Diagnosis: Alzheimer disease	715 (55.7%)
Mixed Alzheimer's and vascular dementia	263 (20.5%)
Vascular dementia	142 (11.1%)
Frontotemporal dementia	45 (3.5%)
Parkinson disease dementia	43 (3.4%)
Dementia with Lewy bodies	43 (3.4%)
Unspecified/other dementia	32 (2.5%)

Notes. Hours of care are the hours of care provided on an average day

descriptive information regardingthe measures is presented in Table 2. Just over two-thirds of the caregivers were women, and the majority were spouses or partners of the participants with dementia. Just over one-half of the people with dementia had a diagnosis of Alzheimer disease.

Correlations between the outcome measures indicate that well-being was strongly correlated with SwL (r= 0.56; n= 1,228; p<0.01). Table 3 reports the unadjusted and adjusted associations of the measures with well-being and SwL. Decreasing trends from high to low categories of caregiving competence and positive aspects of caregiving were apparent for well-being and SwL. Conversely, the increasing trends from low to high categories of caregiving stress and role captivity were

evident for both well-being and SwL. The observed effect sizes were reduced after the inclusion of covariates; however, the trends were still apparent. Lower well-being was associated with low competence (-13.77; 95% confidence interval [CI]: -16.67, -10.87), perceiving fewer positive aspects of caregiving (-7.67; 95% CI: -10.26, -5.01), high caregiving stress (-24.45; 95% CI: -26.94, -21.96), and high role captivity (15.61; 95% CI: -18.33, -12.89). Lower SwL was associated with low competence (-4.62; 95% CI: -5.57, -3.66), perceiving fewer positive aspects of caregiving (-3.09; 95% CI: -3.94, -2.25), high caregiving stress (-7.88; 95% CI: -8.71, -7.06), and high role captivity (-6.41; 95% CI: -7.28, -5.54).

All measures had independent associations with well-being and SwL. The next stage of the analysis was to explore whether these independent associations remained when the measures were considered together. Table 4 reports two adjusted models with caregiving competence and positive aspects of caregiving included in one model, and caregiving stress and role captivity included in another model. The inclusion of both caregiving competence and positive aspects of caregiving into one model resulted in a decrease in effect sizes, but both variables still retained independent associations with well-being and SwL. For the model containing caregiving stress and role captivity, the effect sizes for caregiving stress slightly decreased, but caregiving stress retained an independent association with well-being and SwL. However, the effect sizes for role captivity were considerably attenuated, which suggests that caregiving stress partially explains the association of role captivity with well-being and SwL.

Table 5 reports the adjusted model with caregiving competence, positive aspects of caregiving, caregiving stress, and role captivity included together. The effect sizes for role captivity were reduced further, whereas the effect sizes for caregiving competence were considerably attenuated, suggesting that caregiving stress also partially explains the association between caregiving competence and well-being and SwL. The effect sizes for positive aspects of caregiving were reduced, but still demonstrated an independent association with well-being and SwL. There was little change in the effect size for caregiving stress; thus, caregiving stress retained an independent association with well-being and SwL.

^a Missing data for 51 participants.

^b Missing data for 48 participants.

Positive and Negative Dimensions of Caregiving

TABLE 2.	Caregivers'	Scores on	the Study	Measures

Variables	N (%)	M (SD)	Possible Range	Observed Range	Cronbach's Alpha
Competence	1,238	9.15 (1.68)	3-12	3-12	0.88
Low	297 (24.0)				
Moderate	574 (46.4)				
High	367 (28.6)				
Positive aspects of caregiving	1,234	28.24 (7.38)	9-45	9-45	0.91
Low	562 (45.5)				
Moderate	313 (25.4)				
High	359 (29.1)				
Stress	1,198	19.16 (9.83)	0-60	0-56	0.89
Low	427 (35.6)				
Moderate	373 (31.1)				
High	398 (33.2)				
Role captivity	1,233	5.54 (2.26)	3-12	3-12	0.84
Low	453 (36.7)				
Moderate	440 (35.7)				
High	340 (26.75)				
WHO-5	1,247	55.26 (19.78)	0-100	0-100	0.86
SwLS	1,240	23.77 (6.5)	5-35	5-35	0.88

SD: standard deviation; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

DISCUSSION

To our knowledge, this was the first study to explore the influence of caregiving competence, positive aspects of caregiving, caregiving stress, and role captivity on caregiver well-being and SwL. In this study, we explored both the individual and combined associations of the measures with well-being and SwL. When examined individually, these measures all had independent associations with well-being and SwL. When all the measures were brought together in the same model, only caregiving stress and positive aspects of caregiving retained independent associations with well-being and SwL. When caregiving stress was added into the models that included caregiving competence and role captivity, this resulted in a decrease in effect sizes for caregiving competence and role captivity. Overall, these findings provide evidence that both positive and negative dimensions of caregiving are important for caregivers' well-being and SwL.

Theoretically, there is some debate as to whether the positive and negative dimensions of caregiving are distinct concepts or exist at opposite ends of a continuum. Although there is growing evidence for an association between positive aspects of caregiving and burden, 30,31 only one study has explored the association between positive aspects of caregiving

and caregiving stress.³² The current findings indicate that both these factors have independent associations with well-being and SwL. This finding is similar to the structure of the two-factor models by Kramer⁴ and Lawton et al.¹³ However, both of these models posit that positive and negative dimensions of caregiving will have different associations with specific measures of well-being; for example, positive aspects of caregiving would not be associated with negative affect. In the present study, we found that when a global measure of well-being and SwL were used, both are associated with positive and negative dimensions of caregiving.

When all measures were considered together, only caregiving stress and perceptions of positive aspects of caregiving retained independent associations with well-being and SwL. In addition, the findings indicate that caregiving stress appears to partially explain the association of caregiving competence and role captivity with well-being and SwL. The effect sizes for role captivity were particularly attenuated by caregiving stress. The association between caregiving stress and role captivity is to be expected because these measures reflect different but related negative dimensions of the caregiving experience. The measure of caregiving stress used in this study encompasses emotional distress, social distress, and negative feelings about the role, ³³ whereas role captivity concerns feelings

TABLE 3. Unadjusted and Adjusted Models Showing Individual Associations Between Competence, Positive Aspects of Caregiving, Stress, and Role CaptivityWith Well-Being and SwL

		WHO-5		SwLS		
Unadjusted		Unstandardized Coefficient ^b (95%CI)	t ^c	Unstandardized Coefficient ^b (95% CI)	t ^c	Wald Test ^d
Competence	High	_		_		
_	Moderate	-6.35 (-8.68, -3.84)	-4.97^{a}	-2.48 (-3.30,-1.66)	-5.93^{a}	
	Low	-14.69 (-17.63, -11.76)	-9.83^{a}	-5.21 (-6.17, -4.25)	-10.64^{a}	$F(4,1,209) = 34.73^a$
Positive aspects of caregiving	High	_		_		
0 0	Moderate	-6.29 (-9.25, -3.32)	-4.16^{a}	-2.34(-3.30, -1.37)	-4.76^{a}	
	Low	-8.82 (-11.42,-6.22)	-6.65^{a}	-3.44 (-4.29, -2.60)	-8.00^{a}	$F(4,1,206) = 18.07^{a}$
Stress	Low	_		_		
	Moderate	-12.94 (-15.26, -10.61)	-10.92^{a}	-3.75(-4.52, -2.98)	-9.59^{a}	
	High	-25.59(-27.86, -23.30)	-22.03^{a}	-8.32(-9.07, -7.57)	-21.71^{a}	$F(4, 1, 174) = 173.94^{a}$
Role captivity	Low			_		
	Moderate	-9.05 (-11.49, -6.61)	-7.29^{a}	-3.26(-4.04, -2.50)	-8.27^{a}	
	High	-17.96 (-20.57,-15.34)	-13.48^{a}	-7.12 (-7.95, -6.29)	-16.82^{a}	$F(4, 1,207) = 80.42^{a}$
Adjusted for Careg	iver Gender, Ca	regiver Age, Kin-Relationship, I	Hours Per Wee	ek Spent Providing Care, and	Dementia Dia	gnosis
Competence	High	_		_		
	Moderate	-5.76 (-8.25, -3.26)	-4.52^{a}	-2.24 (-3.07, -1.42)	-5.34^{a}	
	Low	-13.77 (-16.67,-10.87)	-9.31^{a}	-4.62(-5.57, -3.66)	-9.47^{a}	$F(4, 1,151) = 30.03^a$
Positive aspects of caregiving	High	_		_		
	Moderate	-5.42 (-8.34, -2.50)	-3.64^{a}	-2.09(-3.04, -1.14)	-4.31^{a}	
	Low	-7.67 (-10.26, -5.07)	-5.80^{a}	-3.09 (-3.94, -2.25)	-7.19^{a}	$F(4, 1, 149) = 14.71^a$
Stress	Low	_		_		
	Moderate	-12.73 (-15.14, -10.32)	-10.36^{a}	-3.67(-4.46, -2.87)	-9.03^{a}	
	High	-24.45 (-26.94, -21.96)	-19.27^{a}	-7.88 (-8.71, -7.06)	-18.80^{a}	$F(4,1,121)=134.16^{a}$
Role captivity	Low	<u> </u>		<u> </u>		
• •	Moderate	-7.74 (-10.24, -5.24)	-6.08^{a}	-2.84 (-3.64, -2.04)	-7.01^{a}	
	High	-15.61 (-18.33, -12.89)	-11.26 ^a	-6.41 (-7.28, -5.54)	-14.49^{a}	$F(4, 1,150)=59.58^a$

Notes. SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

about being trapped in the caregiving role. Although there is little evidence on the link between caregiving stress and rolecaptivity, role captivity is a strong predictor of burden.³⁴ Both role captivity and lack of caregiving competence are classed as secondary intrapsychic strains in the Stress Process Model, which explores the caregiving stress process.⁵ However, caregiving competence, in particular, has tended to be treated more as a mediator in relation to caregiving stress; for instance, it mediates the association between burden and depression.³⁵ The findings of the current study indicate that in relation to caregiving competence, caregiving stress seems to influence the relationship of caregiving competence with wellbeing and SwL. Therefore, these findings suggest that increase caregivers' feelings of caregiving

competence it may also be important to reduce their levels of stress.

The strengths and limitations of this study need to be considered. The study involved a large cohort of caregivers caring for community-dwelling people with mild-to-moderate stages of dementia. The sample included caregivers from a range of socioeconomic backgrounds and with different kinrelationships to the person with dementia. However, caregivers were primarily the spouses or partners of the person with dementia. The sample was predominantly white British people; future research could explore these associations in a more culturally diverse sample of caregivers. For example, studies have identified differences in the experience of self-efficacy in caregivers from different cultural backgrounds. ³⁶

^ap<0.001.

^bUnstandardized coefficients derived from multivariate linear regression modeling.

^cTest statistic.

^d The Wald test was used to explore whether the measures as a whole were associated with WHO-5 and SwLS.

Positive and Negative Dimensions of Caregiving

TABLE 4. Fully Adjusted Models Showing Associations of Measures of Positive and Negative Dimensions of Caregiving With Well-Being and SwL

		WHO-5		SwLS		
		Unstandardized Coefficient ^c (95% CI)	t ^d	Unstandardized Coefficient ^c (95% CI)	t ^d	Wald Test ^e
Adjusted for Caregiv	er Gender, Careg	iver Age, Kin-Relationship, Hou	rs Per Week Sp	ent Providing Care, and Dem	entia Diagnos	sis
Model 1						
Competence	High	_		_		
•	Moderate	-4.98(-7.51, -2.46)	-3.87^{b}	-1.92(-2.75, -1.09)	-2.22^{b}	
	Low	-12.33 (-15.31, -9.34)	-8.11^{b}	-3.97(-4.94, -2.99)	-3.96^{b}	$F(4, 1, 140) = 22.23^{1}$
Positive aspects of caregiving	High					
	Moderate	-3.27(-6.16, -0.38)	-4.56^{a}	-1.37(-2.31, -0.42)	-2.83^{a}	
	Low	-5.21(-7.79, -2.63)	-7.97^{b}	-2.29(-3.14, -1.45)	-5.32^{b}	$F(4, 1, 140) = 7.77^{b}$
Model 2						
Stress	Low	-		_		
	Moderate	-12.16(-14.82, -9.51)	-8.98^{b}	-2.92(-3.79, -2.05)	-6.60^{b}	
	High	-23.35(-26.47, -20.22)	-14.66^{b}	-6.37 (-7.39, -5.35)	-12.24^{b}	$F(4, 1, 113) = 68.17^{b}$
Role captivity	Low			_		
• •	Moderate	-0.86(-3.40, 1.68)	-0.66	-1.08(-1.91, -0.25)	-2.55^{a}	
	High	-1.58(-4.72, 1.55)	-0.99	-2.61(-3.63, -1.58)	-4.99^{b}	$F(4, 1, 113) = 6.48^{b}$

Notes. SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

TABLE 5. Fully Adjusted Model Showing Associations of Competence, Positive Aspects of Caregiving, Stress, and Role Captivity With Well-Being and SwL

		WHO-5		SwLS		
		Unstandardized Coefficient ^c (95% CI)	t ^d	Unstandardized Coefficient ^c (95% CI)	t ^d	Wald Test ^e
Adjusted for Caregi	ver Gender, Care	egiver Age, Kin-Relationship, Spo	ent Providing (Care, and Dementia Diagnosis		
Competence	High	_		_		
_	Moderate	-1.83(-4.19, 0.53)	-1.52	-0.76 (-1.53 , 0.01)	-1.95	
	Low	-4.84(-7.72, -1.95)	-3.29^{a}	-1.19 (-2.12 , -0.25)	-2.48^{a}	$F(4, 1,005)=3.45^{a}$
Positive aspects of caregiving	High			_		
	Moderate	-2.92(-5.55, -0.29)	-2.18^{a}	-1.30 (-2.16 , -0.45)	-2.99^{a}	
	Low	-3.07(-5.44, -0.70)	-2.54^{a}	-1.58(-2.36, -0.81)	-4.02^{b}	$F(4, 1,105)=4.77^{b}$
Stress	Low			_		
	Moderate	-11.44(-14.11, -8.78)	-8.43^{b}	-2.74(-3.61, -1.87)	-6.20^{b}	
	High	-22.01 (-25.19, -18.83)	-13.58^{b}	-6.02(-7.05, -4.98)	-11.41^{b}	$F(4, 1,105)=59.40^{b}$
Role captivity	Low	_		_		
• •	Moderate	-0.07 (-2.65 , 2.51)	-0.05	-0.71 (-1.55 , 0.13)	-1.65	
	High	-0.53 (-3.7, 2.64)	-0.33	-2.14 (-3.17, -1.11)	-4.07	$F(4, 1,105) = 4.72^{b}$

Notes. SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

^a p<0.05.

^bp<0.001.

 $^{^{\}rm c} \hat{\rm U} n standardized$ coefficients derived from multivariate linear regression modeling.

^d Test statistic.

^e The Wald test was used to explore whether the measures as a whole were associated with WHO-5 and SwLS.

^a p<0.05.

^bp<0.001.

^cUnstandardized coefficients derived from multivariate linear regression modeling.

^d Test statistic, df = 1,274.

^e The Wald test was used to explore whether the measures as a whole were associated with WHO-5 and SwLS.

Quinn et al.

This was a cross-sectional study using time-point onedata from the IDEAL study; however, as IDEAL is a longitudinal study, there is scope in the future to explore the longitudinal influences of these factors on caregiver well-being and SwL.

Both positive and negative dimensions of caregiving contribute to caregiver well-being and SwL. This implies that psychological therapies or interventions aimed at improving caregiver well-being and SwL need to consider the influence of both the positive and negative dimensions of caregiving. Interventions have typically focused on addressing caregiving burden.³⁷ Fewer studies have used caregiving competence, positive aspects of caregiving, caregiving stress,or role captivity as outcomes for interventions.³⁷ Interestingly, interventions typically have nonsignificant effects on decreasing caregiver burden,³⁸ which may be because caregiver burden is the result of multiple nonmodifiable factors, and thus, less amenable to change. Therefore, it may be more feasible for caregiving interventions to target factors that may be more modifiable such as changing caregivers' beliefs about competency in the role or their appraisals of positive aspects of caregiving.

Recognition of the need to address both the positive and negative dimensions of caregiving is growing. Understanding the role of positive aspects of care may help healthcare professionals to appropriately validate caregivers' feelings and experiences. ⁴ A focus on positive aspects of caregiving would also enable a 'strengths perspective' or capabilities approach, recognizing the capacity of the caregiver for continued growth. The development of interventions that aim to simultaneously increase appraisals of positive aspects of caregiving and decrease appraisals of negative aspects of caregiving may be the most beneficial for caregiver well-being and SwL. There is a reciprocal relationship between positive and negative emotional states, and it has been suggested that interventions that cultivate positive emotions can then tackle negative emotions as well as build resilience.³⁹ Some interventions developed specifically for caregivers of people with dementia have focused on both positive and negative dimensions of caregiving, but the results are inconsistent. For example, caregivers taking part in an educational and skills-based training intervention had postintervention decreases in role captivity, but no significant differences in self-efficacy. 40 Conversely, a problem-solving intervention produced improvements in caregiving competence, but not role captivity. ⁴¹ Interventions that tackle caregivers' underlying appraisals of their role may be more effective. Based on the stress and coping model, which concerns the appraisals a person makes in response to a stressor, an intervention that targeted caregiving appraisals was successful in increasing positive aspects of caregiving and decreasing caregiver strain. ⁴² However, the followups were only conducted 30 days postintervention, and further work is needed to explore the long-term benefits of such interventions.

CONCLUSION

To our knowledge, this is the first study to indicate that caregiving competence, positive aspects of caregiving, caregiving stress, and role captivity can influence caregiver well-being and SwL. The findings indicate that support services and interventions need to consider the influence of positive and negative dimensions of caregiving on caregiver well-being and SwL. The findings highlight the importance of exploring both the positive and negative dimensions of the caregiving experience.

The IDEAL study is funded by the Economic and Social Research Council (United Kingdom) and the National Institute for Health Research (United Kingdom) through grant ES/L001853/2 "Improving the experience of dementia and enhancing active life: living well with dementia" (Investigators: L. Clare, I.R. Jones, C. Victor, J.V. Hindle, R.W. Jones, M. Knapp, M.D. Kopelman, R. Litherland, A. Martyr, F. Matthews, R.G. Morris, S.M. Nelis, J. Pickett, C. Quinn, J. Rusted, and J. Thom). The support of the Economic and Social Research Council and National Institute for Health Research is gratefully acknowledged.

The authors would like to acknowledge the support of the following research networks: NIHR Dementias and Neurodegeneration Specialty (DeN-DRoN) in England, the Scottish Dementia Clinical Research Network (SDCRN), and Health and Care Research Wales. The authors gratefully acknowledge the local principal investigators and researchers involved in participant recruitment and assessment within these networks. The authors thank the members of the ALWAYs group and the Project Advisory Group for their support with the study. The authors

Positive and Negative Dimensions of Caregiving

are extremely grateful to Yu-Tzu Wu for her support with statistical analyses and feedback on drafts of the manuscript.

The IDEAL data will be deposited with the UK Data Archive upon completion of the study. Details on how the data can be accessed will be made available on the project website www.idealproject.org.uk.

Author Contributions: Authors CQ, LC, SMN, AM, CV, and RGM were involved in the original conception and design of the project. The lead author, CQ, was responsible for the data analysis and interpretation, and for drafting the article. All authors have contributed to the critical revision of the article and provided final approval of the version to be published.

References

- Department of Health: 2012 Prime Minister's Challenge on Dementia: Delivering Major Improvements in Dementia Care and Research by 2015. London: Department of Health, 2012
- Alzheimer's Association: 2017 Alzheimer's disease facts and figures. Alzheimers Dement 2017; 13:325–373
- Pinquart M, Sörensen S: Differences between caregivers and noncaregivers in psychological health and physical health: a meta analysis. Psychol Aging 2003; 18:250-267
- Kramer BJ: Gain in the caregiving experience: where are we? What next? Gerontologist 1997; 37:218-232
- Pearlin LI, Mullan JT, Semple SJ, et al: Caregiving and the stress process: an overview of concepts and their measures. Gerontologist 1990; 30:583–594
- Manthorpe J, Bowling A: Quality of life measures for carers for people with dementia: measurement issues, gaps in research and promising paths. Res Policy Plan 2016; 31:163–178
- George LK, Gwyther LP: Caregiver well-being: a multidimensional examination of family caregivers of demented adults. Gerontologist 1986; 26:253–259
- Orgeta V, Lo Sterzo E, Orrell M: Assessing mental well-being in family carers of people with dementia using the Warwick-Edinburgh Mental Well-Being Scale. Int Psychogeriatr 2013; 25:1443–1451
- Folkman S: The case for positive emotions in the stress process. Anxiety Stress Coping 2008; 21:3-14
- Carbonneau H, Caron C, Desrosiers J: Development of a conceptual framework of positive aspects of caregiving in dementia. Dementia 2010; 9:327-353
- Quinn C, Clare L, Woods RT: The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. Int Psychogeriatr 2010; 22:43–55
- Quinn C, Toms G: Influence of positive aspects of dementia caregiving on caregivers' well-being: a systematic review[Epub ahead of print]. Gerontologist 2018 Dec 28;doi:10.1093/geront/gny168
- Lawton MP, Moss M, Kleban MH, et al: A two-factor model of caregiving appraisal and psychological well-being. J Gerontol B Psychol Sci Soc Sci 1991; 46:181-189
- Greene JG, Smith R, Gardiner M, et al: Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. Age Ageing 1982; 11:121-126
- Schuz B, Czerniawski A, Davie N, et al: Leisure time activities and mental health in informal dementia caregivers. Appl Psychol Health WellBeing 2015; 7:230–248
- Faba J, Villar F, Giuliani MF: Development of a measure to evaluate gains among spanish dementia caregivers: the gains associated with caregiving (GAC) scale. Arch Gerontol Geriatr 2017; 68:76-83
- Morano CL: Appraisal and coping: moderators or mediators of stress in Alzheimer's disease caregivers? Soc Work Res 2003; 27:116-128

- 18. Alvira MC, Risco E, Cabrera E, et al: The association between positive-negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study. J Adv Nurs 2015; 71:1417–1434
- Lethin C, Renom-Guiteras A, Zwakhalen S, et al: Psychological well-being over time among informal caregivers caring for persons with dementia living at home. Aging Ment Health 2017; 21:1138-1146
- Goncalves-Pereira M, Carmo I, da Silva JA, et al: Caregiving experiences and knowledge about dementia in Portuguese clinical outpatient settings. Int Psychogeriatr 2010; 22:270–280
- Morano CL: The role of appraisal and expressive support in mediating strain and gain in hispanic Alzheimer's disease caregivers. J Ethnic Cult Divers Soc Work 2003; 12:1-18
- Clare L, Nelis SM, Quinn C, et al: Improving the experience of dementia and enhancing active life—living well with dementia: study protocol for the IDEAL study. Health Qual Life Outcomes 2014: 12:164
- Folstein MF, Folstein FE, McHugh PR: "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975; 12:189–198
- 24. Robertson SM, Zarit SH, Duncan LG, et al: Family caregivers' patterns of positive and negative affect. Fam Relat 2007; 56:12–23
- 25. Tarlow BJ, Wisniewski SR, Belle SH, et al: Positive aspects of caregiving: contributions of the REACH project to the development of new measures for Alzheimer's caregiving. Res Aging 2004; 26:429–453
- Bech P: Measuring the dimension of psychological general wellbeing by the WHO-5. Qual Life Newslett 2004; 32:15-16
- Balducci C, Mnich E, McKee KJ, et al: Negative impact and positive value in caregiving: validation of the COPE index in a six-country sample of carers. Gerontologist 2008; 48:276–286
- 28. Diener E, Emmons RA, Larsen RJ, et al: The satisfaction with life scale. J Pers Assess 1985; 49:71–75
- McConaghy R, Caltabiano ML: Caring for a person with dementia: exploring relationships between perceived burden, depression, coping and well-being. Nurs Health Sci 2005; 7:81-91
- Quinn C, Clare L, Woods RT: What predicts whether caregivers of people with dementia find meaning in their role? Int J Geriatr Psychiatry 2012; 27:1195-1202
- Yap P, Luo N, Ng WY, et al: Gain in Alzheimer care instrument—a new scale to measure caregiving gains in dementia. Am J Geriatr Psychiatry 2010; 18:68–76
- Uwakwe R: Satisfaction with dementia care-giving in Nigeria: a pilot investigation. Int J Geriatr Psychiatry 2006; 21:296–297
- Ulstein I, Bruun Wyller T, Engedal K: The relative stress scale, a useful instrument to identify various aspects of carer burden in dementia? Int J Geriatr Psychiatry 2007; 22:61–67
- 34. Campbell P, Wright J, Oyebode J, et al: Determinants of burden in those who care for someone with dementia. Int J Geriatr Psychiatry 2008; 23:1078–1085

Quinn et al.

- Grano C, Lucidi F, Violani C: The relationship between caregiving self-efficacy and depressive symptoms in family caregivers of patients with Alzheimer disease: a longitudinal study. Int Psychogeriatr 2017; 29:1095–1103
- Depp C, Sorocco K, Kasl-Godley J, et al: Caregiver self-efficacy, ethnicity, and kinship differences in dementia caregivers. Am J Geriatr Psychiatry 2005; 13:787–794
- Pendergrass A, Becker C, Hautzinger M, et al: Dementia caregiver interventions: a systematic review of caregiver outcomes and instruments in randomized controlled trials. Int J Emerg Ment Health 2015; 17:459-468
- Laver K, Milte R, Dyer S, et al: A systematic review and meta-analysis comparing carer focused and dyadic multicomponent

- interventions for carers of people with dementia. J Aging Health 2017; 29:1308-1349
- 39. Fredrickson BL: Cultivating positive emotions to optimize health and well-being. Prev Treat 2000; 3:1
- Judge KS, Yarry SJ, Looman WJ, et al: Improved strain and psychosocial outcomes for caregivers of individuals with dementia: findings from project ANSWERS. Gerontologist 2013; 53:280–292
- 41. Chiu M, Wesson V, Sadavoy J: Improving caregiving competence, stress coping, and mental well-being in informal dementia carers. World J Psychiatr 2013; 3:65–73
- **42.** Beauchamp N, Irvine AB, Seeley J, et al: Worksite-based internet multimedia program for family caregivers of persons with dementia. Gerontologist 2005; 45:793–801