Research Article

A Pilot Study on Health-Related Quality of Life and Caregiving Burden of Caregivers for Dementia: A Cross-sectional Report on the Pre-Test Assessment Results

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Abstract

Objectives

Family caregivers of dementia patients were assessed using a survey instrument covering different domains of caregiver burden, physical well-being, social well-being, and psychological well-being.

Methods

In this pilot study, a total of 30 participants receiving home and community based services completed the pre-test survey during the period of April 26, 2015 through September 13, 2015. Demographic and personal characteristics of respondents were gathered from the survey.

Results

The average age for the caregivers was 54. Less than one-fourth of caregivers were spouses of the patients. The three health-related quality of life (HRQOL) indicators are shared in common with the same latent variable, having the factor loading of 0.51 with physical well-being, 0.61 with psychological well-being and 0.84 with social well-being. Those who experienced with poorer HRQOL scores reported with higher scores of caregiving burden. Self-efficacy was a stronger predictor of caregiving burden than the well-being indicators. It did modify the relationship between HRQOL and caregiving burden.

Conclusion

The moderating effect of self-efficacy on caregiving burden and health-related quality of life has been demonstrated in this pilot study. Self-efficacy has a much stronger influence than well-being indicators (HRQOL) on caregiving burden.

Introduction

Alzheimer's disease (AD), an irreversible and progressive disease, is the fourth leading cause of deaths among the elderly in the U.S., following deaths from heart disease, cancer, and stroke. The number of people with AD is expected to reach 12 million in the U.S. Although AD has been better understood from clinical studies, the pathogenesis of AD is not clearly identified. Generally, AD results from brain cell atrophy and death of brain cells due to abnormal accumulation of plagues and neurofibrillary tangles in the nerve cells [1]. Unfortunately, there are no effective treatments or drugs that can completely cure it or delay the occurrence of AD.

It is often noted that caregivers of patients with AD are the second victim of this disease. Because of the progressive and degenerative nature of this disease, taking care of such a chronic condition is an exhausting and emotionally draining job since the patients with AD will become totally dependent upon caregivers for care. The caregivers usually take total responsibility for caring the patients and are excluded from a normal life. This isolation and exhaustion from the caregiving job may cause an extreme depression and loneliness among caregivers. In many situations, caregivers of patients with AD may collapse under tremendous strain and stress.

The purpose of this initial report is to document caregivers' burden, physical-psychological-social well-being and self-efficacy by using a comprehensive assessment survey to measure caregiving burden and caregivers' well-being. The post-test or second assessment survey will be conducted in the following up assessment. In addition, the analysis of the first assessment will help to gain insights into the factors that may explain the variability in caregiving burden and well-being of caregivers.

Conceptual Framework

Health-related quality of life (HRQOL) is an important component of caregiving burden assessment and research. The causal relationship between HRQOL and caregiving burden can be conceived as a reciprocal relationship between these two variables if it is observed in a single time point such as a cross-sectional study. HRQOL may directly affect the variability in caregiving burden. Similarly, caregiving burden may also affect the variability in caregivers' HRQOL. However, the causal specification can be more appropriately examined in a two-wave assessment study (Figure 1).

The present analysis of the data was based on the data collected at the pre-test period only. The assessment of HRQOL was based on the self-reported well-being indicators over a period of three months, whereas the level of caregiving burden was related to the experience in the most recent month. Thus, we examined how the variability in caregiving burden of caregivers of dementia patients may be accounted for by HRQOL and self-efficacy.
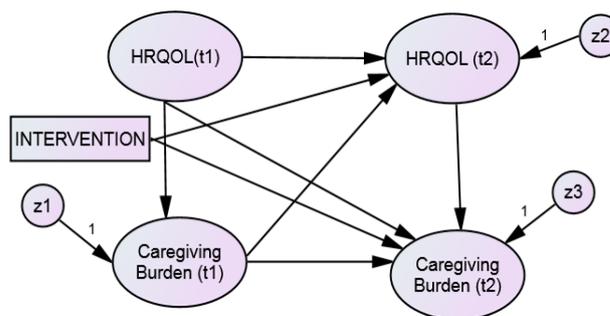

Figure 1. Causal Relationships between Health-Related Quality of Life (HRQOL) and Caregiving Burden for Dementia in A Two-Time Points (t1 and t2).

Method

Study Design

Family caregivers included in this study were recruited from a volunteer group served by Share the Care, Inc., a day-care service provider in the Central Florida area. Enrollment started at any time during the first 6 months of the one year study period. Caregivers signed an informed consent form that allowed Share the Care to release data to the research team. Eligibility criteria of caregivers enrollment were as follows:

1. Inclusion Criteria:

      1) Caregiver must be over the age of 21.

      2) Caregiver lives with and provide care for a people with Alzheimer's disease or another form of dementia for a minimum of 4 hour per day for at least the past 6 months.

2. Exclusion Criteria:

      1) Caregiver refuses to sign an informed consent form.

      2) Caregivers for the patients who have no documentation of Alzheimer's disease or dementia will be excluded.

      3) Caregiver does not have any computer, tablet, or smartphone access.

Caregivers are excluded if they are involved in another caregiver intervention study.

      4) Initially, 30 dementia caregivers who completed the first assessment survey were included in the analysis.

      Basic demographic characteristics of caregivers consist of age, sex, ethnic or racial group, marital status, caregiving hours per week, mobility, and relationship to a care recipient.

Measurement of the Study Variables

a. Caregiving Burden

The dependent variable of caregiver burden was measured by an instrument called the Zarit Burden Interview. This instrument was first proposed in 1980 with 29 items [2]. It has been frequently used in many dementia caregiving studies. In 2001, the 29-items version was modified into 12 items [3].

Each of the 12 items was scored: never =0, rarely = 1, sometimes = 2, very often = 3, and nearly always = 4. The internal consistency of the shorter version of Zarit scale has been confirmed with correlation ranged between 0.92 and 0.97 [3]. The response options for each question item range from 0 (never) to 4 (nearly always); higher scores indicate greater level of caregiving burden. The strength of the Zarit score is related to its high reliability and stability, provided the results on this measure are valid and relatively comparable [4]. Therefore, we can objectively and effectively analyze the burden level of caregivers.

a. Physical Well-being

The independent variable of caregiver's physical well-being was measured by the EuroQoL, five dimensions questionnaire to reflect the extent of a respondent's physical function or independence. The EQ-5D is a self-reported questionnaire developed by the EuroQoL group to measure health-related quality of life on the five dimensions of mobility, self-care, usual activities, discomfort/pain and depression/anxiety [5]. Each dimension is rated on a three-point scale, containing 1) no problem, 2) some problem, and 3) extreme problem. There is an analog-version of the EuroQoL available. We adopted EQ-5D for its simplicity in scoring responses without consuming too much time in the assessment. The caregivers were asked to indicate their health condition by selecting an appropriate option of each dimension. The total score was a summation of all five dimension scores, and it was used to portray the respondents' physical health. The EQ-5D is very suitable for use in a wide range of health conditions [6].

Psychological Well-being

A short version of the Center for Epidemiologic Studies-Depression Scale (CES-D) was used to measure a caregiver's psychological wellbeing. This scale consists of 10 items developed by Lenore Sawyer Radloff [7] at the National Institute of Mental Health, and it has been validated empirically for its validity and reliability in studies of depressive symptoms [8, 9].

The response options for each item on the psychological well-being scale are from 0 (rarely or none of the time; less than 1 day) through 3 (all the time; 5-7 days). The scores of two items (Items 5 and 8) were reversed to reflect the same direction as other item scores. The aggregate scores range from 0 to 30. A higher score indicates a higher level of depression. The validity and sensitivity of this scale have been confirmed by previous studies [10 – 12]. The validity of the CES-D has been demonstrated across different socio-demographic groups in a general population and but also shown in cross-cultural research [13].

Social well-being

The independent variable of social well-being was measured by the Satisfaction with Life Scale, which is a 5-item scale that measures life satisfaction as a cognitive-judgmental process [14]. Subjective social indicators are based on the premise that personal perceptions can validly and reliably reflect a respondent's own social wellbeing. The Satisfaction with Life Scale has been widely used to assess an individual's social well-being. A high score indicates a poorer social well-being.

Self-efficacy

Self-efficacy was another independent variable that refers to a person's belief about her or his ability to organize and execute courses of action to manage a given situation [15]. Self-efficacy plays an important role in portraying coping ability or psycho-social functioning in two ways. First, self-efficacy determines coping behaviors when people face obstacles and aversive experiences. Second, self-efficacy affects vulnerability to emotional stress. In a series of studies, self-efficacy was used to explain the experiences of family caregivers of persons with dementia. Steffen et al [16] modified the scale of self-efficacy for caregivers with 15 questions. Each item can be answered affirmatively (0) or negatively (1). Higher scores indicate lower levels of self-efficacy.

Analytical Methods

Both descriptive and multivariate statistical analyses were performed. The analysis of variance, correlation, and regression analysis, and structural equation modeling were used to examine the relationship between well-being indicators and caregiving burden when self-efficacy was also considered. One-way analysis of variance (ANOVA) was performed to determine how each demographic and personal attribute of caregivers accounted for any variance in caregiving burden, well-being indicators and self-efficacy independently. The statistical significance level was based on the alpha level of 0.05.

Results

Descriptive Analysis

Higher scores of caregiving burden indicate greater levels of caregiving burden. Higher scores of psychological well-being indicate lower levels of psychological well-being. Similarly, physical well-being, social well-being, and self-efficacy are also scored the same way as psychological well-being; the lower the score, the higher the functional ability.

The demographic attributes of the sample are presented in Table 1. Of the 30 caregivers included in the analysis of the first survey results, 90% were female. The mean age was 54

(SD=11.8). White caregivers accounted for 33% whereas African American caregivers had 27%. Caregivers constitute only 23% of patients' spouses. A majority of caregivers (83.3%) were married.

Table 1. Sample Demographics of Caregivers at the Baseline (N=30).

Demographic attributes	Mean or Percentage
Age (Average, SD)	54.0 (11.8)
Female	90.0
Race of caregivers	
White	33.0
African American	27.0
Other	40.0
Marital status	
Married	83.3
Single	16.7
Relationship between caregiver and care recipient	
Spouse	23.0
Not spouse	77.0

Statistical Analysis

The results of ANOVA showed only one statistically significant variable that physical well-being was explained by the relationship with the care recipient.

A correlation matrix for the relationship of the three well-being indicators and self-efficacy to caregiving burden is presented in Table 3. The Pearson correlation coefficients show the following results: 1) the caregiving burden scores were statistically significantly associated with psychological well-being (0.421) but not physical well-being and social well-being indicators; 2) physical well-being was positively and moderately associated with social well-being indicator (0.444) ; 3) psychological well-being was positively associated with social well-being (0.631); and 4) self-efficacy was not significantly associated with the three well-being indicators, but it was significantly associated with the caregiving burden score (0.523). There is no problem regarding multicollinearity between the independents, as no correlation coefficient is equal to or greater than 0.7.

Regression analysis was performed using the caregiving burden score as a dependent variable and the well-being indicators and self-efficacy as predictor variables without demographic attributes as control variables. Table 4 shows that self-efficacy was statistically significant related to the level of caregiving burden when the effects of well-being indicators were simultaneously controlled. If the self-efficacy score of a given caregiver increases by one, the predicted increase in the observed score of caregiving burden for this caregiver would be .441 (standardized beta). For each additional unit of increase in self-efficacy score, the expected score of caregiving burden increases 1.019. The three well-being indicators were not statistically significant predictors of caregiving burden in this regression model when the influence of self-efficacy was controlled.

Table 2. ANOVA of Demographic Attributes of Caregivers for Caregiving Burden, Well-being Indicators and Self Efficacy.

Demographic Attributes	Caregiving burden		Physical well-being		Psychological well-being		Social Well-being		Self-efficacy	
	F	P	F	P	F	P	F	P	F	P
Gender	1.642	.211	.001	.982	.618	.438	0.263	.612	.381	.542
Race	.219	.805	.271	.765	2.116	.142	1.434	.257	.586	.564
Marital status	.554	.463	3.009	.094	.105	.748	.063	.804	.598	.446
Relationship with care recipient	.029	.867	4.154	.050	1.413	.244	.034	.854	.804	.377
Caregiving burden	1.36	.27	1.00	.38	.39	.68	.52	.60	.31	.73
Mean score*	24.20		8.63		16.40		14.70		6.30	
Standard deviation	6.531		2.580		4.461		4.808		2.830	
Range	13-41		5-15		8-30		7-24		1-13	

*Mean score for each scale used.

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Caregiving burden as a dependent variable can be analyzed by structural equation model, using the latent variable of three well-being indicators and self-efficacy measure as predictor variables. Figure 2 presents the parameter estimates and shows that the well-being construct, as a latent variable, and self-efficacy account for a relatively larger variance in the variability of caregiving burden than HRQOL. In order to reduce caregiving burden of caregivers, it is imperative to improve the self-efficacy level in handling stress or burden.

cause the scales of HRQOL indicators were scored in a reverse direction, higher scores represent poorer levels of well-being or health-related quality of life. The relationship between poor HRQOL and caregiving burden (C-Burden) was positively and statistically significantly related (with a regression coefficient of 0.43) without controlling for the effect of self-efficacy. However, when self-efficacy was introduced in the model, the relationship between HRQOL and caregiving burden was attenuated with a net effect of 0.21 (Figure 2).

Table 3. Pearson Correlations of Well-being Indicators and Self-Efficacy with Caregiving Burden.

|	Caregiving burden	Physical well-being	Psychological well-being	Social well-being	Self-efficacy
Caregiving burden	1				
Physical well-being	.250	1			
Psychological well-being	.421*	.235	1		
Social well-being	.263	.444*	.631**	1	
Self-efficacy	.523*	.313	.241	.270	1

*. Correlation is significant at the 0.05 level (2-tailed)
**. Correlation is significant at the 0.01 level (2-tailed).

Table 4. Multiple Regression Analysis of Caregiving Burden.

Model	Unstandardized Coefficients		Standardized Coefficients	t	*P*-value
	Std. Error	Beta	B		
(Constant)	9.550	4.788		1.995	.057
physical well-being	.205	.460	.081	.446	.659
Psychological well-being	.553	.301	.377	1.837	.078
Social well-being	-.177	.301	-.130	-.587	.562
Self-efficacy	1.019	.391	.441	2.62	.015

Figure 2. Physical-Psychological-Social Well-Being and Self-Efficacy as Predictors of Caregiving Burden of Caregivers for Dementia.
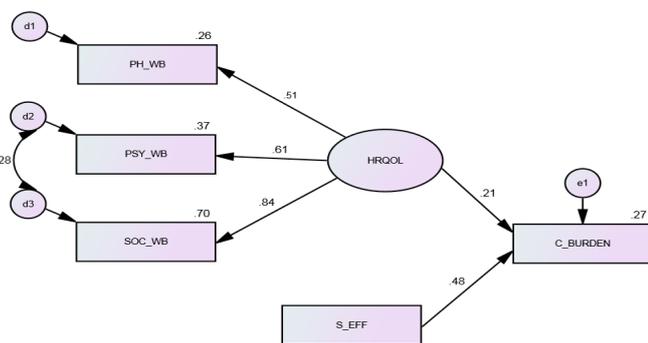
Notes: All parameter estimates are statistically significant at 0.05 level.

The examination of health related quality of life (HRQOL) indicators, using structural equation modeling, shows that a common variance shared by the three related indicators. Be-

The influence of self-efficacy on caregiving burden was moderately strong and statistically significant (0.48). Self-efficacy (S-EFF) appears to modify the relationship between HRQOL and C-Burden. The total variance explained by both HRQOL and self-efficacy for caregiving burden was 27%. Structural equation modeling offers a unique view on model fitting. If a specified model is well fitted by the data, it will result in a small Chi-square value; the larger the Chi-square, the poorer the model fit is observed. The overall goodness of fit (GOF) statistics for this model was demonstrated with a Chi-square value of 7.82 for 5 degrees of freedom at the P-value of 0.17 as shown in the SEM results, using SPSS-AMOS software.

Discussion

Major Findings

The analysis of the pre-test or first assessment survey data from 30 caregivers offers some informative results. First, the descriptive analysis clarifies the basic demographic attributes, self-reported levels of well-being, and perception of

caregiving burden. These results portrayed the variability in demographic attributes of the caregivers and also showed the heterogeneity of caregiving experiences and situations. This information will enhance our ability to formulate research questions for a randomized controlled study in future intervention studies.

Second, the positive associations among the well-being indicators show the expected results as observed by previous research [17, 18]. The health-related quality of life as a latent variable is shared in common by the three indicators as shown in the measurement model.

Third, from the ANOVA analysis of selected demographic attributes, we concluded that the spouse-recipient relationship and marital status are two important demographic attributes in caregiving burden and well-being indicators.

Fourth, regression analysis revealed that self-efficacy had a much stronger influence on the levels of caregiving burden than the well-being indicators. The psychological well-being is the only statistically significant indicator that accounts for the variability in caregiving burden when other well-being indicators and self-efficacy are simultaneously considered.

Fifth, self-efficacy is a moderating variable or moderator between health-related quality of life and caregiving burden. As poor well-being may adversely influence caregiving burden, self-efficacy could serve as a buffering factor of the relationship between these two variables.

Limitations

There are several limitations in this pre-test report. First, the sample size in this report is relatively small, and a larger sample size is needed to increase the diversity of caregivers' attributes in future study in order to increase the generalizability of the results. Second, missing values in the data which could have resulted the biased estimates of regression parameters. Collecting more data from a representative sample of caregivers will allow for more accurate and explanatory models developed. Third, it is challenging in gaining access to caregivers and their patients through adult day care centers. In order to increase the sample size, investigators should explore other avenues such as recruiting study subjects from caregivers' associations or participants in area agencies on aging in varying communities.

Research and Practice Implications

Caregivers of dementia may experience varying levels of caregiving burden and stress. However, they are not homogenous groups of people residing in the community. This pilot study reveals that those had higher levels of caregiving burden and also experienced lower levels of health-related quality of life or well-being. This implies that intervention programs for reducing caregiving burden of caregivers should identify their initial well-being status. Future research should target on the early stage of caregiving experience and also tease out the causal effect of poor well-being

on later experience of caregiving burden. Furthermore, assesment of well-being and caregiving burden should be part of the evaluation of dementia care programs [19, 20].

Attention to enhance self-perceived efficacy in handling stress and burden associated with caregiving should be made. Clinical or social work practice in dementia care should develop practical strategies to implement a comprehensive assessment of health-related quality of life and a series of coping mechanisms of caregivers. Thus, effective interventions can be systematically formulated to promote preventive services for them.

Conclusion

The present study will continue gathering the data from the participants in a follow-up assessment. Although the moderating effect of self-efficacy on the relationship between HRQOL and caregiving burden has been demonstrated in this pilot study, the causal-specific relationship between health-related quality of life and caregiving burden could only be ascertained thoroughly by a longitudinal study. The moderating effect of self-efficacy to be enhanced through the use of any creative caregiving activities or guides should be conducted in a large sample of a clinical trial study.

Conflict of Interest

The authors declare no conflict of interest in this research.

Acknowledgement

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