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Relationship between subjective and objective burden in family caregivers of Alzheimer patients

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The aim of this work is to determine the role that social support, coping, optimism, quality of life, resilience and life satisfaction have on the relationship between objective and subjective burden on family caregivers of Alzheimer patients. Method: Participants: 140 caregivers of Alzheimer patients. Instruments: Sociodemographic Data; CBI Caregiver Burden Scale; COPE Coping Styles Scale; DUKE.UNC Social Support Scale; LOT-R, Life Orientation Test-Revised; QOLLTI-F, Quality of Life in Life Threatening Illness Scale–Family Carers Version; CD-RISC, Connor-Davidson Resilience Scale; SWLS, Satisfaction with Life Scale. Procedure: Implementation of scales in an individual, voluntary, anonymous way, including informed consent. Results: All variables studied produced significant differences between caregivers with high and low subjective burden, except time caring measured in months/years. Relationships between the variables were significant, with the exception of months/years caring and coping styles. Social support, optimism, satisfaction and quality of life have an important mediating role between objective and subjective burden. Conclusions and discussion: Social support, optimism, satisfaction and quality of life have been decisive as mediating variables between hours a day taking care (objective burden) and subjective burden. This result represents a step forward in the analysis and subsequent creation of intervention programs in family caregivers.

Keywords: objective burden, subjective burden, differences, relationship, mediation.

Relación entre la carga objetiva y la carga subjetiva en cuidadores familiares de enfermos de Alzheimer. El objetivo del trabajo es determinar el papel de apoyo social, afrontamiento, optimismo, calidad de vida, resiliencia y satisfacción con la vida en la relación entre carga objetiva y subjetiva en cuidadores familiares de enfermos de Alzheimer. Método: Participantes: 140 cuidadores familiares de enfermos de Alzheimer. Instrumentos: Registro sociodemográfico; CBI, Escala de Carga del Cuidador; COPE, Escala de Estilos de Afrontamiento; DUKE.UNC, Escala de Apoyo Social; LOT-R, Test de Orientación en la Vida; QOLLTI-F, Escala de Calidad de Vida en Cuidadores de Enfermos Graves; CD-RISC, Escala de Resiliencia; SWLS, Escala de Satisfacción con la Vida. Procedimiento: Cumplimentación de escalas de modo individual, voluntario, anónimo, con consentimiento informado. Resultados: Todas las variables dan lugar a diferencias significativas entre cuidadores con alta carga subjetiva y baja carga subjetiva, a excepción de meses/años cuidando; así como a relaciones significativas entre ellas, con la excepción de meses/años cuidando y afrontamiento. Apoyo social, optimismo, satisfacción y calidad de vida presentan un importante papel mediador entre carga objetiva y subjetiva. Conclusiones y discusión: Apoyo social, optimismo, satisfacción y calidad de vida han sido determinantes como variables mediadoras entre horas al día cuidando (carga objetiva) y carga subjetiva. Este resultado supone un avance significativo en el análisis y creación de programas de intervención en cuidadores familiares.

Keywords: carga objetiva, carga subjetiva, diferencias, relación, mediación.

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Alzheimer's disease (AD) is characterized by cognitive symptoms, physical problems and emotional disturbances, with a trend towards an increasingly deteriorating state and increased dependence in the patient (Pool, 2002). According to the World Health Organization (WHO) in 2010 there were 35.6 million people with Alzheimer's disease in the world, and increasing 7.7 million each year. Accordingly, the estimated population of patients for 2016 would be around 81.8 million (WHO, 2013). The very high levels of dependency that occur in people suffering from this disease in terminal stage make it essential the care of such patients by the people closest to them, their family.

The family is the first source of help and care for Alzheimer's patients, care that has been referred to as "familiar", "informal" or "non-professional" to distinguish it from that provided by health professionals. Within family care, the variable burden, because of the high levels detected in caregivers, has been the variable that has focused most research, especially in caregivers of patients with dementia (Pearlin, 1992).

When dealing with the burden on caregivers of dependents, objective and subjective components have to be distinguished, with objective burden focusing on the caregiver role performance. "The time caring, the physical tasks, the objective activities performed by the caregiver and the exposure to stressful situations regarding care, are examples of objectively burden indicators frequently used" (pg. 87; Garcia Mateo and Maroto, 2004). On the other hand, the subjective burden focuses on how the caregiver perceives the care situation, especially the emotional response to these care tasks.

Cognitive, behavioral and emotional declining functions associated with the progression of Alzheimer's disease, make the care of patients with this disease more difficult and associated to higher burden, both objective and subjective, than caring for other patients (Arai, Zarit, and Sugiura, 2002; Laserna et al., 1997; Ory, Hoffman, Yee, Tebbstedt, and Schulz, 1999). In this context, a study on the needs of the primary caregiver of Alzheimer's patient in terminal phase concluded that the activity involving greater burden was hygiene (80%), to which the caregivers dedicated 77% of its time. Thus, the bath-toilet was the task that entailed greater burden on the caregiver and in which he/she needed more help. In addition, caregivers considered the need for help in other activities such as nutrition management, medication, mobilization in postural changes and prevention of pressure ulcers (Mears and Sánchez, 2005).

Most of burden research on caregivers have searched the elements that accompany a high subjective burden, such as large periods of time caring measured in years of care (Roig, Abengozar, and Serra, 1998; Garcia et al., 2004; Larrañaga, et al., 2008) or in hours of daily caring (Badia, Lara, and Roset, 2004); the greatest impact that care for a dependent produce in the caregiver life (Montorio, Fernandez Lopez, and Sánchez, 1998); the specific dementia phase in the patient (Artaso, Goñi, and Biurrun, 2003), the psychopathological symptoms, especially depression and anxiety (Garre-Olmo et al., 2002), the low social support (Molina, Ibanez, and Ibanez, 2005), the low assertiveness (Muela, Torres, and Peláez, 2001) or the use of inadequate coping strategies (Colmenero, Pelaez, and Muela, 2002).

Also, from the Pearlin's Stress Model Adapted to Care Situations (Pearling 1992; Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch, 1995; Pearlin and Skaff, 1995; Gaugler, Zarit, and Pearlin, 1999), three important cores are raised in the way the care for a dependent affects the caregiver. First, the primary and secondary stressors, directly and indirectly respectively associated with the task of care and where the objective caregiver burden would be found. Second, the final result of the duty of care, where it could settle the subjective burden, that is, perception that each caregiver has of the objective burden. Finally, as a third core, the mediating variables are presented, which are those whose involvement influences the relationship between the stressors and the final result, namely, social support and coping strategies variables.

Another anchor point at the theoretical level of the work presented here is confined to the positive effects of caring for a family dependent, and the relationship with Positive Psychology. Variables such as optimism, life satisfaction and resilience have shown high predictive power of physical health, mental health and quality of life of people in high-stress situations (Scheier, Carver, and Bridges, 2001; Seligman, 2002; García, Sanjuán, and Pérez, 2003; Wrosch and Scheier, 2003).

Based on the above, the objective of our work was to test the mediating variables proposed by Pearlin, social support and coping strategies in caregivers of Alzheimer patients, which have added other relevant variables from Positive Psychology such as quality of life, optimism, life satisfaction and resilience. These variables should show their mediating role between the stressor, objectively measured by time caring, and the final result measured by the caregivers' subjective burden.

METHOD

Participants

The sample was made up of 140 family caregivers of Alzheimer patients from the Associations of Alzheimer patients in Valencian towns: Alcoy, Cocentaina, Muro de Alcoy, Ibi and Villena. They were mostly sons/daughters (67.9%), women (68.6%), married (84.3%) and with an age range from 18 to 91 years old.

Instruments

Family caregivers completed the following scales, where reliability in the present sample is also consigned. The socio-demographic variables collected were age, gender, hours/day caring, months caring, severity of the disease in the Alzheimer's disease relative cared for and perception of physical health; CBI, Caregiver Burden Scale (Zarit, Reever, and Bach-Peterson, 1980) assessed the perception of the caregiver burden (α=.85);

Coping Styles Scale, COPE (Carver, 1997) evaluated active (*α*=.87) and avoidant (*α*=.65) coping styles; DUKE.UNC, Social Support Scale (Broadhead, Gehlbach, DeGruy, and Kaplan, 1988) measured perceived social support (*α*=.89); LOT-R, Life Orientation Test-Revised (Scheier, Carver and Bridges, 1994) assessed dispositional optimism (*α*=.72); QOLLTI-F, Quality of Life in Life Threatening Illness Scale–Family Carers Version (Cohen et al., 2006) evaluated the quality of life of caregivers of patients with severe disease (*α*=.81); SWLS, Satisfaction with Life Scale, (Diener, Emmons, Larsen, and Griffin, 1985) which assessed life satisfaction (*α*=.82), and finally CD-RISC (Connor y Davidson, 2003) assessed resilience (*α*=.85).

Procedure

In the first place, we contacted the associations mentioned in the participants' description. Secondly, we got the informed agreement of those caregivers who expressed a desire to participate in the study. Then, the instruments described were provided to the family caregivers. An identification number was assigned to them in order to preserve the participants' anonymity. Once the scales were completed, the data was introduced in the statistical program SPSS 21 to perform subsequent analyses.

Data analysis

Data concerning differences analysis were obtained through the Student's *t* test and Cohen's *d*; the correlation analysis through Pearson correlations, mediational analysis using Sobel test, and finally multiple regression analysis was performed including variables with a full and partial mediation between objective and subjective burden.

RESULTS

Differences obtained between caregivers with high and low burden were significant in all the variables studied except in the specific variable of objective burden, months/years caring (see table 1). All differences showed high effect sizes with the exception of other variable of objective burden: months/years caring. So, the characteristic profile of a caregiver of Alzheimer's patient with high perceived burden versus low burden would be one that cares many hours a day, using mostly coping styles both active and avoidant, but with low levels in the variables social support, quality of life, optimism, life satisfaction and resilience.

As table 2 indicates, most of the variables have significant relationships between them with two clear exceptions: months/years caring and active coping. Months/years caring only showed significant relationship to resilience, in the sense that long periods of care lead to more resilience in the caregivers. As for the active coping style, it is associated with both poorer quality of life and the use of avoidant coping style.

The other variables follow a pattern in which the variables’ group: hours/day caring, subjective burden and coping were positively related; the variables´ group: social support, quality of life, optimism, life satisfaction and resilience were also related positively, but the first group is negatively related with the second one.

Table 1. Differences between caregivers with high and low burden

	Burden	*N*	*M*	*SD*	*t*	*d*
Months/years caring	Low	70	47.11	33.32	-1.5	.23
	High	70	55.94	36.35		
Hours/day caring	Low	70	1.61	1.27	-2.16*	.34
	High	70	2.04	1.07		
Active coping	Low	70	23.37	10.14	-3.53***	.60
	High	70	29.11	9.11		
Avoidant coping	Low	70	3.57	3.35	-3.75***	.67
	High	70	5.76	3.55		
Social support	Low	70	44.29	7.62	4.34***	.80
	High	70	38.26	8.77		
Quality of life	Low	70	113.03	20.12	4.80***	.84
	High	70	97.56	18.00		
Optimism	Low	70	16.09	4.04	2.92**	.75
	High	70	13.94	4.62		
Satisfaction with life	Low	70	17.30	3.06	5.01***	.85
	High	70	14.29	4.00		
Resilience	Low	70	92.43	10.23	4.12***	.76
	High	70	84.83	11.53		

Note: **p* <.05; ***p* <.01; ****p* <.001

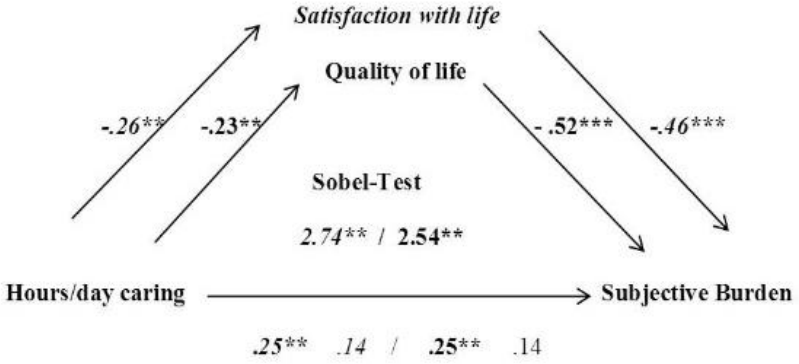
Table 2. Relationships between the variables

	1	2	3	4	5	6	7	8	9	10
1. Months/years caring	---									
2. Hours/day caring		---								
3. Burden	.03	.25**	---							
4. Active coping	.06	.15	.33***	---						
5. Avoidant coping	.09	.08	.38***	.44***	---					
6. Social support	.03	-.26**	-.38***	-.07	-.22**	---				
7. Quality of life	.03	-.23**	-.52***	-.17*	-.27**	.38***	---			
8. Optimism	.01	-.21*	-.29***	-.12	-.20*	.39***	.36***	---		
9. Satisfaction with life	-.02	-.26**	-.46***	-.01	-.18*	.57***	.44***	.41***	---	
10. Resilience	.21*	-.02	-.37***	.06	-.18*	.31***	.36***	.45***	.44***	---

Note: **p*<.05; ***p*<.01; ****p* <.001

Figure 1 shows the full mediating role of life satisfaction and quality of life between the objective burden variable, hours/day caring, and subjective burden. Life satisfaction and quality of life present significant Sobel Tests of 2.74 (*p*>.01) and 2.54 (*p*>.01) respectively with a change in the predictive value of hours/day caring in subjective burden from .25 (*p*>.01) to .14 (not significant) in both variables.

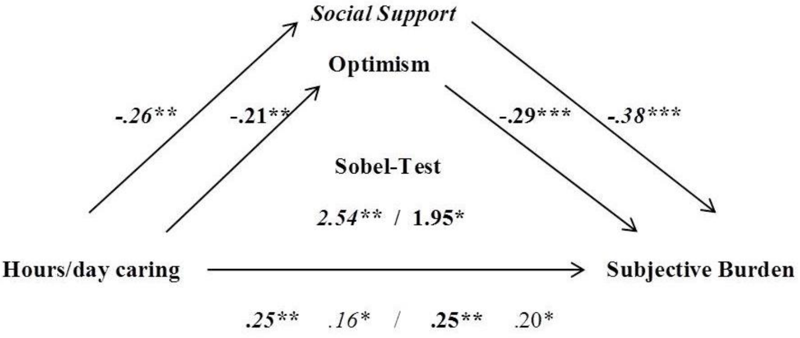
Figure 1. Full Mediation of Satisfaction and Quality of life between Hours/day caring and Subjective burden (Data for Satisfaction with life in italics)



Note: ***p*<.01; ****p* <.001

As shown in figure 2, mediation does not become full, remaining only partial, for the variables social support and optimism. Although in both variables Sobel tests are significant, the predictive value of hours/day caring towards subjective burden changed from .25 (*p*<.01) to .16 (*p*>.05) for social support and to .20 (*p*>. 05) for optimism.

Figure 2. Partial Mediation of Optimism and Quality of life between Hours a day caring and Subjective burden (Data for Social Support in italics)



Note: **p*<.05; ***p* <.001; ****p* <.001

A linear regression with the introduction of variables presenting full mediation, quality of life and life satisfaction, between hours/day caring and subjective burden was performed. High significant Fs were obtained in the tree models. Hours/day caring in Model 1 was a highly predictor variable (β=.25, *p*<.01) but in Models 2 and 3 lost its predictive role (β=.10, p<.190) when the quality of life (β=- 49, *p*<.001 in Model 2 and β=- 38, *p*<.001 in Model 3) and satisfaction with life (β=- 27, *p*<.001) were introduced into the analysis, both with high predictive level of subjective burden. The results indicate that satisfaction and quality of life together have a more important predictive role in subjective burden than the objective burden variable, hours/day caring.

Table 3. Multiple Stepwise Regression with perceived burden as dependent variable and hours/day caring, quality of life and satisfaction with life as predictive variables

Standardized Beta Coefficients				
	F	Hours/day caring	Quality of life	Satisfaction with life
Model 1	9.38**	.25**		
Model 2	27.48***	.14	-.49***	
Model 3	23.48***	.10	-.38***	-.27***

Note: ***p*<.01; ***=*p*<.001.

DISCUSSION AND CONCLUSIONS

Months and years caring, as the first objective burden variable, seems to play only a minor role in the perception of subjective burden on caregivers of Alzheimer patients, a result that did not support those studies which found that more objective burden led to more subjective burden (García et al., 2004; Larrañaga et al., 2008). Rather, results from this variable appear to support the thesis of adaptation to the task of care (Novak and Guest, 1989; Lanzón and Diaz, 2014), explained by their association with greater resilience in the caregiver after having cared for more months and years, supporting the results from the study of Townsend, Noelker, Deimling, and Bass (1989), which found that caregivers of patients with dementia who were in a more advanced phase of the disease were more resilient.

As regards to the second objective burden variable, hours/day caring, it has proved to have a very important role in the perception of subjective burden. Differential and relational results showed that caregivers caring for more hours a day presented more subjective burden. But the most interesting aspect about this variable is the highly significant relationships with all variables in the study. Although in the relational analysis subjective burden was not associated with coping styles and resilience, in the differential analyses caregivers with high levels of subjective burden showed significantly less resilience and high level of coping styles both active and avoidant. The numerous relationships of hours/day caring and subjective burden with most of the variables led us to the performance of mediational analysis, as a way to find out the possible mediating role of the variables studied. The results have identified two variables that produced a full mediation and two other variables with a partial mediation. Life satisfaction and quality of life, with a full mediation, intervened drastically reducing the perceived burden in the caregiver. With regard to social support and optimism, with a partial mediation, its effects were not as important as in the case of the above variables. These results, while confirming the mediating role of social support, do not support the mediating role of coping strategies (Pearlin, 1992; Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch, 1995; Pearlin and Skaff, 1995; Gaugler, Zarit, and Pearlin, 1999). The stepwise regression analysis confirmed the high predictive role of satisfaction and quality of life, reducing the effect of hours per day caring in the subjective burden perceived by the caregiver. In conclusion, based on our results, the mediating variables in the Pearlin's Stress Model Adapted to Care Situations (Pearling 1992; Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch, 1995; Pearlin and Skaff, 1995; Gaugler, Zarit, and Pearlin, 1999) should be extended to include quality of life, life satisfaction and optimism. Therefore, we find that the proposals of Positive Psychology should be taken into account in the explanatory models of objective and subjective burden relationship on family caregivers of dependents.

Finally, we can conclude that the mediating role of quality of life and satisfaction with life in the caregiver is high in the relation between objective burden and subjective burden, which in our study outperform the classical "social support" and "styles coping“ mediating variables" (Pearling, 1992, Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch, 1995; Pearlin and Skaff, 1995; Gaugler, Zarit, and Pearlin, 1999), so an extension of the Pearlin's model arises in which variables associated to Positive Psychology should be included. An indirect conclusion of the work presented here refers to objective burden, in the sense that it seems that the time measured in months and years caring for a family dependent has a minor role in the perception of subjective burden, perhaps due to the adaptation of the caregivers to their care situation (Novak and Guest, 1989; Lanzón and Díaz, 2014), compared to the variable hours a day caring. Our results confirm the importance of including positive variables in interventions in caregivers, since these variables, by increasing quality of life and satisfaction with life, dramatically reduce the perceived burden of caregivers

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