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Positive Aspects of Family Caregiving of Dependent Elderly

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Previous research recently revealed the presence of positive aspects in caregiving. This study had a double objective: first, to identify positive aspects of family caregiving; second, to analyze the relationship between these caregiving rewards and different variables. A total of 140 family caregivers of dependent elderly participated in the study. Out of these, 79 of the elderly suffered dementia and 63 were institutionalized. Caregivers' satisfaction and quality of life was above average. Those caregivers who perceived a good *quality of relationship* with their elder presented more satisfaction than the others. Problems in quality of life showed a positive relationship with the level of dependence of the elder. On the other hand, the more level of dependence of the elder, the greater the level of satisfaction of the caregiver. Those caregivers with a good relationship showed less *provisional meaning* than those with a normal or a bad relationship. We confirm the relevance of the caregiver-elder relationship, which can be improved and modified through specific preventive interventions. Our findings indicate that interventions for caregivers of people with dementia should explore ways to find meaning in caregiving.

Negative consequences of caregiving (burden, anxiety, depression) have been extensively studied for the last three decades. However, the studies focused on positive aspects are few in comparison with those on caregiver burden. It is increasingly recognized that caring for an ill relative can also be a source of positive change in a person's life. Positive and negative aspects of caregiving can coexist (Andren & Elmstahl, 2005; Boerner, Schulz, & Horowitz, 2004; Cohen, Colantonio, & Vernich, 2002; Hunt, 2003; Kramer, 1997; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Noonan & Tennstedt, 1997; Pushkar et al., 1995).

POSITIVE ASPECTS OF CAREGIVING

Caregiving has the potential to be a source of positive transformations in people's lives and can give rise to a sense of satisfaction and meaningfulness, company, and joy for meeting their obligations and knowing that they are performing a vital and caring role for a loved one. Caregiving can be a rewarding experience and facilitate personal growing and maturity (Cohen et al., 2002; Given et al., 1992; Lawton, Kleban, Moos, Rovine, & Glicksman, 1989; Lawton et al., 1991; Mendez-Luck, Kennedy, & Wallace, 2008; Picot, Youngblut, & Zeller, 1997).

Among the most frequently studied positive aspects of caregiving, we are going to focus on satisfaction and quality of life. Life satisfaction is a cognitive component of subjective

well-being, and was defined by Diener, Suh, Lucas, and Smith (1999) as the positive appreciation that people make about their life in general or in specific aspects specific aspects of life such as family, friends, work, leisure, and so on). Quality of life is defined by the World Health Organization as the perception that the person has of his position in life, in the cultural and value context in which he lives. This perception is related with the goals, expectations, standards, and worries that a person has.

DEMOGRAPHIC VARIABLES

Different variables have been related with positive aspects of caregiving. A positive relationship between the caregiver's age and life satisfaction has been proven (Andren & Elmstahl, 2005; Tung & Hu, 2010) as well as between the caregiver's age and quality of life (Andren & Elmstahl, 2005; Azpiazu et al., 2003). However, some research shows evidence that younger caregivers feel greater satisfaction (Kinney & Stephens, 1989; Kramer, 1993).

Regarding caregivers' sex, some studies show that women find more agreeable aspects in caregiving (Kinney & Stephens, 1989; Pushkar et al., 1995). Nevertheless, Ekwall & Hallberg (2007) found greater life satisfaction among male caregivers, Pinquart & Sörensen (2006) found in their meta-analysis that women present lower subjective well-being than men. A poorer quality of life (Azpiazu et al., 2002; Fernández Capo, 2005; Karlawish, Casarett, Klocinski, & Clark, 2001; Thomas et al., 2006) and more strain has been found in women than in men (Perkins et al., 2013). Other studies found that the family caregiver's gender did not influence the degree of life satisfaction (Andren & Elmstahl, 2005).

FINDING MEANING IN CAREGIVING

One way in which caregivers can positively appraise the caregiving situation is to find a meaning in it. Finding meaning involves making sense and giving order and coherence to one's existence (Reker et al., 1987, as cited in Quinn, Clare, & Woods, 2012). There has been limited research that has explored finding meaning in dementia caregiving. However, a systematic review of a small number of studies indicated that finding a meaning could have a positive impact on dementia caregivers' well-being (Quinn et al., 2012). There would be two meaning levels (Farran, 1997): a *provisional meaning*, referring to the day-to-day or short caregivers' experiences in which they can see a positive response to their caregiving in the older adult, feeling confidence in their care providing, and having the subjective experience that they are changing and growing; and there can be an *ultimate meaning*, referring to a deeper sense of life meaning, which usually includes a spiritual content.

RELATIONSHIP BETWEEN CAREGIVER AND ELDER

Relationship quality (between caregivers and older adults) is a highly relevant variable related to meaning and caregiving satisfaction. Research on caregivers of older adults found that a better relationship quality and greater intrinsic motivations can result in caregivers reporting higher levels of satisfaction (Boerner et al., 2004; Fernández Capo, 2005; Lyonette & Yardley, 2003; Motenko, 1989). A poor precaregiving relationship quality has been linked to lower dementia

caregiving satisfaction (Andren & Elmstahl, 2005; Kramer, 1993); a better precaregiving relationship quality was linked to higher reported positive aspects of dementia caregiving (Cohen, Gold, Shulman, & Zuccherro, 1994). However, a study with a mixed sample of caregivers of people with dementia and elders (Mafullul & Morris, 2000) found no link between relationship quality and positive aspects of providing care.

CONTEXT OF CAREGIVING VARIABLES

Caregivers' quality of life seems dependent on dementia type and severity (the more the severity, the less the quality of life) (Andren & Elmstahl, 2005; Azpiazu et al., 2002; Fernández Capo, 2005; Karlawish et al., 2001; Thomas et al., 2006). Pushkar et al. (1995) found that satisfaction decreases as the level of dependence of the elder increases.

An especially interesting variable, due to the scarce research carried out on it, is the place of residence of the dependent elder. The role of the caregiver after the institutionalization of the elder has been little studied, although some studies (Chen, Sabir, Zimmerman, Sutor, & Pillemer, 2007; Garity, 2006; Janzen, 2001; Williams, Zimmerman, & Williams, 2013) have shown that the caregiver role remains as well as his/her level of involvement: the tasks and worries do change, but not the reality of caregiving.

The present study has a double objective: first, to verify the presence of positive aspects of family caregiving of dependent older adults; second, to analyze the relationship between these caregiving rewards and some relevant variables. Specifically, we will focus on sex, age, relationship quality, caregiving meaning, elders' level of dependence, presence of dementia, and place of residence of the elderly.

METHODS

Participants

Participants included 140 family caregivers who met the criterion of being the main family caregiver of a dependent elder adult for at least the previous six months. Table 1 describes the demographic characteristics of the participants. Table 2 specifies the distribution of two variables of the elderly: having dementia and place of residence. Most participants (93.6%) decided voluntarily to become a family caregiver.

Variables and Measures

Demographic Characteristics

Participants indicated their age, gender, marital status, kinship with the dependent adult (husband, wife, son/daughter, other), and whether or not they had dependent children.

Perceived Quality of the Relationship with the Elderly

Caregivers reported on how they felt about the quality of the relationship using a scale from 1 (*conflictive, troubled*) to 4 (*great intimacy and love*).

TABLE 1
Caregivers characteristics (N= 140)

Variables	N	%	Mean/SD
Age	140		61.78/ 10.85
Sex			
Female	95	67.9	
Male	45	32.1	
Kinship with elderly			
Daughter	53	37.9	
Husband	27	19.3	
Wife	24	17.1	
Son	22	15.7	
Others	14	10	
Marital status			
Never married	18	12.9	
Married	116	82.9	
Separated/divorced	2	1.4	
Widowed	3	2.1	
Others	1	0.7	
Dependent children			
Yes	109	77.9	
No	31	22.1	

Presence and Type of Diagnosed Dementia

Caregivers chose one of the following options: vascular dementia, frontotemporal dementia, dementia with Lewy bodies, Alzheimer's disease, or others.

Elderly Level of Dependence

Participants answered the Katz Index of Activities of Daily Living (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963). This instrument is a tool for assessing an older adult's baseline ability to bathe, dress, use the toilet, transfer, remain continent and feed her- or himself; the tool offers an autonomy-dependence index. Caregivers have to estimate the autonomy of their elder as dependent or independent in each of the six basic activity areas and rate the elderly person's dependence level from A (*maximum independence*) to H (*maximum dependence*). The Katz index has shown a Cronbach's alpha from .85 to .86 and a Kappa index of expert agreement

TABLE 2
Distribution of elderly

	Home	Institutionalized	Total
Demented elderly	47	32	79
Older without dementia	30	31	61
Total	77	63	140

of .84 (Álvarez et al., 1992, as cited in López, 2006; Gough & Hudson, 2009). Reliability in our study has been good (Cronbach's alpha .80).

Caregiving Meaning

We used the Spanish version of the Finding Meaning Through Caregiving Scale (Farran, Miller, Kaufman, Fogg, & Fogg, 1999) found in Fernández Capó (2005). Reliability in our study has been good (Cronbach's alpha .89). The scale consists of 43 items measuring three factors: (a) Loss/Powerlessness (19 items), (b) Provisional Meaning (19 items), and (c) Ultimate Meaning (5 items). All items were rated on a 5-point Likert-type scale ranging from 1 (*totally agree*) to 5 (*totally disagree*). Loss/Powerlessness (rated from 19 to 95 points) measures feelings of loss for the family member and for the self, as well as feelings of powerlessness associated with caregiving. It includes items such as "I am sad about losing the person I once knew." Provisional Meaning (rated from 19 to 95 points) measures positive aspects and the ways in which the caregivers find meaning through the caregiving experience with items such as "Caring for my relative gives my life a purpose and a sense of meaning." Ultimate Meaning (rated from 5 to 25 points) focuses on a higher power or religious/spiritual structure in which the caregiver finds meaning. This includes aspects such as "I believe in the power of prayer; without it I couldn't do this." A total score of meaning (ranged from 43 to 215 points) is obtained by adding the three subscales scores (scores of Loss were reversed coded).

Caregiving Satisfaction

We used the Caregiving Satisfaction Scale (one of the subscales found in the Caregiving Appraisal Scale (Lawton, Moss, Hoffman, & Perkinson, 2000). It measures caregiving satisfaction by indicating the level of agreement with statements such as "I get a sense of satisfaction through helping my (elder)." The scale consists of a 6-point Likert-type scale ranging from *never* to *nearly always* or *strongly agree* to *strongly disagree*). Satisfaction total score is rated from 6 to 30. Internal consistency ranged from .67 to .76 (Lawton et al., 1989, as cited in López, 2006). Reliability in our study has been good (Cronbach's alpha .87).

Caregivers' Quality of Life

Participants were asked to answer EuroQoL (EuroQoL, 1990). The EQ-5D is a measure of self-reported health outcomes that is applicable to a wide range of health conditions and treatments. It consists of two parts: a descriptive system (Part I) and a visual analogue scale (VAS) (Part II). Part I of the scale consists of five single-item dimensions including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has a three-point response scale designed to indicate the level of the problem. Part II uses a vertical graduated VAS (thermometer) to measure health status, ranging from worst imaginable health state to best imaginable health state. Descriptive data from the five dimensions of Part I can be used to generate a health-related quality of life profile for the subject. Some studies evaluating test-retest reliability have demonstrated this is high for both individual items ($r = .90$) and for all health states considered simultaneously ($r = .86$). Reliability in our sample has been low (Cronbach's alpha .58). We considered the decision of not including this scale in our further analysis due to

its low reliability. Nevertheless, there are some experts that suggest the need to consider other criteria besides Cronbach's alpha to make such an important decision. We followed the recommendations of Elosua & Zumbo (2008) and Sijstma (2009) and considered the theoretical relevance of this variable, and we decided to include it in the results; however, these need to be carefully interpreted.

Procedure

Various centers were considered for the data collection of this study but were not selected randomly. Specifically, we contacted some associations for Alzheimer's patient's relatives, parishes, hospitals, and residences for the elderly. Each center was contacted by phone and received a personal visit, during which the directors were told about the general objectives of the study and permission was requested for the questionnaires. In some cases participants filled in the questionnaire and sent it by post; and in other cases (when a reply by post was not possible), a personal interview to collect the information needed was carried out. Both the participants and the data collected in this study were treated according to the ethical principles of scientific research.

Data Analysis

We used *t*-Student tests to compare means between two independent groups; we used Welch's correction when we found deviations from variance homogeneity. We used ANOVA to compare means among groups; and when a significant effect was detected, we used Tukey's tests or the Games-Howell test for pair comparisons. We used Pearson correlation to evaluate the relationship between quantitative variables. To analyze caregiving meaning, we used a MANOVA with the three meaning subscales as dependent variables and the different independent variables considered in our study (sex, relationship, internalization, elder dementia, and elder dependence).

In the case of significant results, we present Cohen's *d* and eta-square as effect size measures. Finally, descriptive data present mean and standard deviation (MEAN \pm SD). We set α -level at .05, although when we did many tests with the same variables (e.g., satisfaction, quality of life and quality of life problems by *sex*) inside the same statistical framework (*t* test) we correct α -level by the Bonferroni correction in order to adjust for Type I error ($\alpha = .017$).

RESULTS

Positive Aspects of Caregiving and Associated Variables

Caregivers satisfaction in our study was above average (mean = 25.01, *SD* = 7.02), and they considered themselves to have a remarkable quality of life (71.16 ± 19.04), presenting few related problems (6.22 ± 1.32). Also, men (78.93 ± 16.46) perceived a better quality of life than women (67.47 ± 19.14) ($t_{138} = 3.45$; $p = .001$; $d = 0.61$). Men (5.69 ± 1.00) presented fewer problems related to their quality of life than women (6.47 ± 1.39) ($t_{116.3} = -3.81$; $p < .001$;

$d=0.62$). There was no relationship between *sex* and caregivers' satisfaction ($t_{138}=0.16$; $p=.87$).

Caregivers' satisfaction depends on the relationship with the elder ($F2, 137 = 19.57$; $p < .001$; $\eta^2 = .22$). Those caregivers who perceived a good quality of relationship with their elder ($n = 64$; 27.59 ± 3.01) presented more satisfaction than those who perceived their relationship as "normal" ($n = 50$; 23.48 ± 5.69) (Games-Howell, $p < .001$) or "troubled" ($n = 26$; 21.58 ± 5.73) (Games-Howell, $p < .001$). Also, we found differences in the number of problems related to the quality of life in the function of the relationship between the caregiver and the elder ($F2, 137 = 6.72$; $p = .002$; $\eta^2 = .089$). Caregivers with a bad relationship presented more problems ($n = 26$; 6.92 ± 1.52) than those with a normal relationship ($n = 50$; 5.80 ± 1.01) (Games-Howell, $p = .005$). We did not find differences with those caregivers with a good relationship ($n = 64$; 6.27 ± 1.35). Finally, caregivers did not perceive differences in their quality of life in relation to the elder relationship ($F2, 137 = 1.12$; $p = .33$).

We did not find differences in function if the elderly has a diagnosis of dementia in caregivers' satisfaction ($t_{138} = -0.24$; $p = .81$) neither in caregivers' perception of their quality of life ($t_{138} = 0.77$; $p = .44$) nor in their problems related to this subject ($t_{138} = 0.32$; $p = .75$). Also, if the elder was not institutionalized, this showed no relationship with these variables (quality of life: $t_{138} = -1.00$; $p = .32$, and quality of life problems: $t_{138} = -0.77$; $p = .44$).

Elder level of dependence is positively related with caregiver satisfaction, the more the level of dependence of the elder, the more the level of satisfaction of the caregiver ($n = 140$; $r = .214$; $p = .01$). On the other hand, elder level of dependence is positively related with caregivers' quality of life problems ($n = 140$; $r = .246$; $p = .003$), caregivers show more problems of their quality of life when the level of dependence of the elder increases. We did not find a relationship between quality of life and elder dependence ($n = 140$; $r = -.065$; $p = .44$).

Caregiving Meaning

Caregivers' scores on caregiving meaning are presented in Table 3. We can see that the scores in the three domains are lower than those obtained by Farran et al. (1999) and Fernández-Capo (2005).

We examined associations between caregiving meaning and the positive aspects of caregiving (Table 4). The association between meaning and quality of life was only significant for the powerlessness/loss scale, so those caregivers with higher scores in the powerlessness scale reported lower scores in quality of life. Meanwhile, the caregivers who perceived their provisional meaning or ultimate meaning as higher reported a greater level of satisfaction.

TABLE 3
Caregivers Scores in Finding Meaning Through Caregiving Scale ($N=140$)

<i>Variable</i>	Mean	SD	<i>Ranged</i>
Loss/Powerlessness	56.59	17.10	19–95
Provisional Meaning	35.16	13.44	19–91
Ultimate Meaning	10.99	5.58	5–25
Total Meaning	102.74	23.19	54–179

TABLE 4
Correlations between meaning, satisfaction, and quality of life ($n = 140$)

	Meaning*		
	Powerlessness/Loss	Provisional	Ultimate
Satisfaction	.064	-.668	-.416
Quality of life	.415	-.053	.020
Quality of life problems	-.393	-.045	-.013

*Significant correlations are in bold, α -level was set by Bonferroni correction for nine tests (critical value, $p = .0056$).

We found no differences in meaning in relation to the sex of the caregiver ($F3, 136 = 1.39$; $p = .25$). On the other hand, the meaning of the caregiver depends on the relationship with the elder ($F6, 272 = 3.58$; $p = .002$; $\eta^2 = .073$). Univariate analysis revealed an effect of the elder's relationship on the provisional meaning ($F2, 137 = 11.40$; $p < .001$; $\eta^2 = .014$), those caregivers with a good relationship showed less provisional meaning ($n = 64$; 29.70 ± 7.89) than those with a normal ($n = 50$; 39.04 ± 16.42) (Games-Howell, $p = .001$) or a bad relationship ($n = 26$; 41.12 ± 13.25) (Games-Howell, $p = .001$).

We have found an effect of the dementia of the elder on meaning ($F3, 136 = 9.77$; $p < .001$; $\eta^2 = .18$). Univariate analysis showed a relationship between dementia and powerlessness and loss ($F1, 138 = 23.83$; $p < 0.001$; $\eta^2 = .15$), dementia elder caregivers showed less powerlessness and loss (50.85 ± 15.84) than nondementia caregivers (64.03 ± 15.85).

Meaning variables show differences in function of institutionalization of the elder ($F3, 136 = 9.75$; $p < 0.001$; $\eta^2 = .18$); this effect appears in provisional ($F1, 138 = 4.02$; $p = 0.047$; $\eta^2 = .03$) and ultimate meanings ($F1, 138 = 9.63$; $p = 0.002$; $\eta^2 = .06$). Caregivers that live with the elder show greater provisional (37.19 ± 15.49) and less ultimate (9.70 ± 5.33) meaning than the caregivers where the elder is institutionalized (provisional: 32.67 ± 9.96 ; ultimate: 12.56 ± 5.52).

Finally we did not find any relationship between the level of dependence of the elder and any of the variables of meaning: powerlessness and loss ($n = 140$; $r = -.137$; $p = .10$), provisional meaning ($n = 140$; $r = -.153$; $p = .07$), or ultimate meaning ($n = 140$; $r = .052$; $p = .54$).

DISCUSSION

One of the objectives in our study was to verify the presence of positive aspects of family caregiving of dependent elder adults. Our participants are satisfied with their caregiving, showing higher levels than those found by Crespo & López (2006) or Lawton et al., (1989). They consider that they have a remarkable quality of life (71 out of 100), just four points below the Spanish population and above that shown by people over 65 (Azpiazu et al., 2002). Freeman, Surosawa, Ebihara, and Kohzuki (2009) found that caregivers of dependent elderly had worse quality of life than the general population, but our data do not support that assertion. We can say that caregivers are capable of finding rewarding aspects in caregiving despite the emotional strain of providing care.

Our second objective was to analyze the relationship between the caregiving positive aspects and different variables. We found that male caregivers perceive a better quality of life than

female, along the same line as other studies (Azpiazu et al., 2002; Ruigómez, Alonso, & Anto, 1991; Thomas et al., 2006). Women in our country used to have lower educative levels, lower economic income, worse health status, and a higher level of dependence than men, variables that can contribute to explain the quality of life differences we have found.

It is interesting to point out that the presence or absence of dementia has no relation with caregivers' perception of satisfaction or quality of life, but it does affect the elderly's level of dependence. The more dependent the elderly, the lower caregivers' quality of life and lower caregivers' satisfaction. The more dependent the elderly, the greater are the efforts needed to help them dress, eat, wash, etc. (Rogeró, 2009). Caregivers increase caregiving time and reduce leisure time, overloading with hard work that finally damages their own health status, and they feel they have no strength and are overwhelmed by the situation.

One of the most relevant variables associated with caregiving rewards is the perceived quality of caregiver-elder relationship. If the relationship is perceived as positive (intimacy, love), caregivers report better quality of life and greater satisfaction. Conversely, if the relationship is perceived as conflictive, the caregiver's satisfaction perception decreases the same way that quality of life does. Boerner et al. (2004), Fauth et al. (2012), Fernández Capo (2005), and Lyonette & Yardley (2003) had previously found this association. Our findings support the idea that the perception of positive consequences in caregiving does not depend on objective situation variables (i.e., number of caregiving hours) but on relational aspects like closeness, motivation, or caregiver's personality traits (Pinquart & Sörensen, 2003).

Meanwhile caregivers with high levels of provisional meaning and ultimate meaning show greater satisfaction. Provisional meaning is found by caregivers when the elderly live at home; ultimate meaning is frequently perceived by caregivers whose elderly are already institutionalized. A possible explanation for this relationship could be that caregivers whose family remains in the home are responsible for carrying out the daily tasks of care. This responsibility is essential for them to make sense of situations and needs that are faced daily and that frequently involve a confrontation between the hard reality that they have to live with and losses they are experiencing. At the time when the patient is institutionalized, finding meaning in the daily task becomes less important, becoming the spiritual meaning and religious beliefs or practices at the core of the person.

Our results indicate that caregivers of older people with dementia have a significantly greater loss of meaning than caregivers of elderly without cognitive impairment. Older people with dementia have a number of problems and needs are increasing along with the disease; caring for a person with this disease is an ongoing farewell, as the person gradually loses all his/her abilities and personality. So sometimes the caregiver can despair and suffer from fatigue, making it difficult to find a meaning to care. Therefore, it is essential to help caregivers of elders with dementia find a meaning so they can cope with their difficult task. In contrast, caregivers of elderly without dementia show increased provisional meaning over caregivers of elderly with dementia.

LIMITATIONS AND STRENGTHS OF THE STUDY

There are several limitations to our study that should be taken into account when interpreting the results. First of all, it is important to emphasize that sample limitations make it difficult to

generalize the results and conclusions of this study. Due to the difficulty of accessing this type of sample and convincing subjects to participate in the study, we used an incidental sample selected from those subjects who met the inclusion criteria.

Secondly, using self-reporting assessment instruments could entail distortions or sources of error, specifically in quality of life scores (due its low reliability). Thirdly, the type of design used in this study, cross-sectional and quasiexperimental, does not allow for direct cause-effect relations to be established.

To conclude, in spite of the limitations mentioned, we consider that the study has some strengths that give greater validity to its conclusions: First, the focus on positive aspects is relatively new and interesting for research as well as for practical considerations. Second, we have confirmed the extraordinary relevance of the caregiver–elder relationship, a variable that can be trained and modified through specific preventive interventions. It would be appropriate to help families to experience more and more positive emotional experiences when the elder lives at home as when he/she has been institutionalized. Finally, the findings from the current study indicate that interventions for caregivers of people with dementia should explore meaning. Finding meaning is an individual process, and it is recognized that interventions may not be able to directly enable caregivers to find meaning. However, interventions could help caregivers to appraise the situation more positively, which could eventually result in them finding meaning (Quinn et al., 2012).

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