

Involvement in self-care and psychological well-being of Spanish family caregivers of relatives with dementia

Beatriz Alonso-Cortés PhD¹, Ramón González-Cabanach PhD², Jesús Seco-Calvo PhD³

¹*SALBIS Research Group, Faculty of Health Sciences, University of León, Ponferrada, Spain*

²*Department of Evolutionary Psychology and Education, University of A Coruña, A Coruña, Spain*

³*Institute of Biomedicine (IBIOMED), Faculty of Health Sciences, University of León, Spain*

Correspondence. Beatriz Alonso-Cortés, SALBIS Research Group, Faculty of Health Sciences, Campus of Ponferrada, University of León, 24401 Ponferrada, Spain. Email: balof@unileon.es

Abstract

The provision of continuous care to a dependent person can lead to a lack of self-care by the caregiver themselves with corresponding low levels of well-being. This well-being has been analysed mostly from within the perspective of the hedonic tradition, with the development of personal growth often being overlooked. This study aims to increase the understanding of the connection between this type of psychological well-being and involvement in self-care activities, and to be a starting point for the determination of categories that may serve in the screening of potential participants in social-health interventions where it is being promoted. Taking the hypothesis of a probable positive connection between *psychological well-being* and *involvement in self-care*, an observational study was carried out on 45 caregivers of relatives with dementia. In those caregivers showing greater dedication to self-care, a higher score was obtained on the well-being scales connected to personal significance and positive emotions and experiences. These findings were further reinforced by the identification of other positive connections, the involvement in self-care and the six dimensions of wellness contemplated by Ryff. It is possible to envisage the existence of a virtuous circle in respect of the caregiver, whereby a greater involvement in self-care is related to a higher psychological well-being, which in turn is related to greater self-care, and so on.

Keywords

Caregivers, personal growth, self-care, well-being

1 INTRODUCTION

Our society has to address the issue of taking care of a large number of dependent individuals who are defined as ‘people who, for reasons linked to the lack or loss of physical, mental or intellectual capacity, need assistance or important help in the realisation of activities of daily life’ (MATS, 2005).

Although this care can be given by friends and neighbours, it is the family system that provides it most frequently (86% of cases), and in more than half of homes, it is provided by one person only (López & Crespo, 2008). The provision of this continuing care of a dependent person, especially if they have dementia, is a situation which generates distress (Schulz & Martire, 2004), whose impact seems to be related more to the assessment made of the situation by the caregiver themselves, and to the personal resources available to manage it, than to the characteristics of the situation itself (López & Crespo, 2007). This distress, together with the high emotional burden involved in continuous care-giving, gives rise to negative consequences in several ways.

From the social point of view, the provision of continuous care causes an increase in isolation, a worsening financial situation (Rodríguez et al., 2000) and a greater need for the use of medical services (Draper, Poulos, Cole, Poulos, & Ehrlich, 1992). Furthermore, continuous care also leads to a potential neglect of self-care behaviours, such as taking a little daily exercise (Fuller-Jonap & Haley, 1995; Gallant & Connell, 1997); it can also precipitate other less healthy patterns of behaviour.

From the point of view of physical and psychological aspects, there are frequently observed problems linked to the musculoskeletal system (Muñoz-Cruzado y Barba, 2008), as well as the incidence of anxiety, depression or overburden (López & Crespo, 2007; Pinquart & Sörensen, 2003), among others.

In spite of this being known, there is still a certain lack of knowledge about the condition of certain psychological dimensions, such as psychological well-being (Ryan & Deci, 2001). Such well-being, which is sometimes illustrated by multidimensional models such as Ryff's theoretical model of psychological well-being for better management (Díaz et al., 2006; Ryff, 1989), focuses on the development of personal growth and capabilities, unlike the one which focuses on life satisfaction and happiness (subjective).

A better understanding of this topic is therefore required. The aim of this research is to increase the knowledge of the relationship between this psychological well-being and certain aspects linked to caregivers' lifestyles such as their involvement in self-care.

2 MATERIALS AND METHODS

2.1 Study and eligibility criteria

This was an observational study conducted on a sample of family caregivers of dependent elderly people, being members of several Spanish provincial branches of the confederation 'Associations of Relatives of Alzheimer's and other dementias'. The present study was approved by the Department of Evolutionary Psychology and Education of the Universidad de A Coruña.

The following were included in the inclusion criteria for taking part in the study: being of legal age, identifying oneself as the primary caregiver of a dependent person, having a direct relationship with the dependent person and providing continuous care for a period of at least 1 year.

2.2 Procedure

The empirical part of this work, which took place during the first semester of 2009, began with the holding of several meetings with the managers of five associations. The members of the associations were informed of the objectives of the programme and its stages, as well as the exclusion and inclusion criteria. Among the inclusion criteria, the caregiver should be the main person responsible for the care of the relative with dementia, and should have performed this task for a minimum period of 1 year. Of the 50 members who requested to be part of the study, five had to be eliminated. Once the participant members were selected ($n = 45$) and the informed consent obtained, their evaluations began, being based on a personal interview and the completion of three questionnaires.

The personal interviews were divided into three parts: the first was designed to obtain information about the *personal characteristics of the caregivers* (gender, age, family relationship, level of education and regional context); the second on the *general characteristics of the care situations* (responsibilities of care, the tasks involved, time

dedicated as a caregiver and the level of functional dependency of the relative); the third part assessed the *involvement in self-care* by the caregiver.

The questions asked regarding the variables in the first two parts were based on questions previously included in the Initial Interview Guidelines for Caregivers (López & Crespo, 2007) and in other studies carried out on family caregivers (Losada-Baltar, Trocóniz, Montorio-Cerrato, Márquez-González, & Pérez-Rojo, 2004).

In the third part, a question was included about the involvement in self-care health behaviours (*How much time do you spend taking care of yourself weekly?*), based on the Expert Patients Programme (EPP) from the University of Stanford (SMRC, 2018). Regarding this same question, caregivers were informed of the importance of considering only the time devoted to the practice of therapeutic exercise involving classic (aerobic, flexibility and strength) and body–mind modalities (breathing exercises, yoga, among others), while avoiding the inclusion of any time spent on activities such as the use of medical services and related aspects (taking medication and others), the purchase of special foods, researching/reading of health information, watching television or listening to music.

The investigation also included the completion of three questionnaires by the caregivers: (a) the dependence index according to the Barthel index (Mahoney & Barthel, 1965), which assesses the functional capacity of 10 activities of daily living; (b) the perception of burden, quantified through the caregiver's burden scale (Martín et al., 1996); and (c) the Ryff scale of 39 items (Díaz et al., 2006), which proposes a structure of six factors of well-being: *Self-acceptance*, *Positive relationships*, *Autonomy*, *Environmental Mastery*, *Purpose in life* and *Personal growth*.

2.3 Statistical analysis

For the systematisation and statistical analysis of the data collected, the statistical package IBM SPSS Statistics 19.0 was used, taking as reference a statistical significance value of 0.05. This study included the descriptive analysis of the sociodemographic factors of the caregivers and the results obtained from the analysis of the two variables on which the research was focused. This analysis included the determination of mean values and standard deviations or percentages. For the comparison of means the Mann–Whitney [*U*] and Kruskal–Wallis's [*H*] tests were used for the variables with non-normal distribution,

while for variables with normal distribution the *t*-student [*t*] test was applied for independent samples and one-way ANOVA [*A*]. Correlations were calculated using the test of Spearman [*S*].

3 RESULTS

Regarding the *personal characteristics of the caregiver*, the mean age of the caregivers was 61.3 ± 10.3 years (males = 75.4 ± 4.33 and females = 59.5 ± 9.48). Of the 45 caregivers included, a clear majority were women (88.9%), while men only represented 11.1%. Regarding the *family relationship*, caregivers attended mostly to first-degree relatives, being in most cases their daughters/sons (46.7%) and spouses (40%). Regarding the *level of education*, it was observed that 53.3% of the caregivers had achieved a secondary level, 20% primary level, 20% being illiterate and 6.7% had completed a tertiary level. Concerning *regional context*, 57.8% were from urban communities while the remaining 42.2% were from rural areas. With respect to the *caregiver's perceived burden*, 60% of caregivers were found to be severely affected by the burden (scores between 56 and 110); 28.9% were found to be mildly affected (scores between 47 and 55) and 11.1% were found to be unaffected (scores between 22–46), according to the parameters established in the Zarit questionnaire.

In relation to the *general characteristics of the care situation*, the sample presented a mean value of 70.1 ± 45.6 months in respect of *time dedicated to caregiving*. The analysis of the data for the three categories considered revealed that a total of 18 caregivers have been dedicated to continuous care tasks for fewer than 60 months, 21 between 60 and 120 months and 6 for more than 120 months. Regarding *responsibility for care*, similar percentages were found between the two categories studied, with the tasks being assumed alone by 52.8% of the caregivers and shared by 48.9%. With reference to the *occupation of the caregivers*, 61.1% carried out some paid work activity, as opposed to 38.9% who were exclusively dedicated to caregiving tasks. The *level of dependency* of the family member assisted, which was analysed using the Barthel index, showed that 60% of the family members assisted were highly dependent (total and severe); 24.4% were moderately or poorly dependent and 15.6% were independent.

The data on the results concerning the two principal variables of the research are shown in Table 1. With regard to the *psychological well-being* of the caregivers, the mean scores were calculated for the six sub-scales. Regarding *involvement in self-care* activities, we decided to summarise the behaviours around this variable into three categories, as a complement to that postulated in the EPP: (a) a first category that included caregivers *Not involved in self-care*; (b) a second category including those who presented an involvement in self-care of less than 3 hr a week, referred to as *Slightly involved in self-care*; and (c) the caregivers showing an involvement in self-care of more than 3 hr a week, a category classified as *Highly involved in self-care*. Regarding the distribution of caregivers around this variable, it is worth noting the similar percentages found among the highly involved caregivers (44.4%) and those who were not involved at all in self-care activities (40%). When asked about the reasons for the absence of self-care activities, 61.1% replied that it was due to lack of time, 22.2% due to lack of interest and 16% referred to other reasons, such as lack of training or family problems.

The statistical treatment also included a comparison of mean values of the *personal characteristics of the caregiver* and the *general characteristics of the care situation*, for the two principal variables under study (Table 2).

Regarding the *psychological well-being* of the family caregivers, we found significant results for the *positive relations* ($p = 0.045$) and *personal growth* scales ($p = 0.038$) for the *time dedicated as caregivers*, so that the caregivers who had been performing the care tasks for longer periods were also those with greater social relationships and higher personal growth. We also found a statistical relationship between the *environmental mastery* scale and the *perceived burden* ($p = 0.020$), so that those caregivers who perceived themselves to be most affected by burden, presented the lowest scores on the above-mentioned psychological well-being scale.

Analysing the *time of involvement in self-care*, we only found significant differences with respect to the *regional context* ($p = 0.009$), the participants from rural areas being those who dedicated more time to themselves, in comparison to those from the urban context.

For the two principal variables studied in this work (*Psychological well-being* and *the time of Involvement in self-care*), a correlation study was also carried out (Table 3). Of the relationships studied, all of them were positive and it is worth highlighting those observed in the two dimensions that represent psychological well-being in a more genuine

way, purpose in life and personal growth, and the scales traditionally more associated with subjective well-being: environmental mastery and self-acceptance.

Regarding the results of the analysis of *psychological well-being* for the different categories of *involvement in self-care* (Table 4), it is important to highlight that the caregivers who were highly involved in their self-care obtained higher scores in *purpose in life* and *personal growth* scales, compared to those who were not involved. This was also found in *autonomy scale*, as well as *environmental mastery* and *self-acceptance*.

4 DISCUSSION

The characterisation of the sample studied is similar to that found in several works also focused in caregivers of dependent persons (Ferrando, Canal, Motjé, Centellas, & Roura, 2006; Losada-Baltar et al., 2004). The caregivers were mainly female, daughters or wives of the relative receiving the care, and with a specific level of education. As far as the participants' age and family relationship were concerned, we have found studies that present similar data to ours regarding the mean age (Navarro, Mederos, & Riera, 1999; Slachevsky et al., 2013) and a higher percentage of daughters than wives (Muñoz-Cruzado y Barba et al., 2008). Other studies report a higher mean age (Ponce, 2010) and a higher percentage of spouses (Ocaña, Vinuesa, Robles, & Castro, 2007). Regarding the caregivers' age, it is interesting to comment on the notable percentage of primary caregivers over 60 years old (40%), which confirms what was expressed by Kramer and Thompson (2001) about an increasing number of older adults that assume these tasks. In relation to the percentage of caregivers in our study with intense burden (55.6%), we have found studies that show similar or even higher burden rates: 55.5% (Alonso-Babarro, Garrido-Barral, Matín-Martínez, & Francisco-Morejón, 2005), 62.9% (Slachevsky et al., 2013) and 83.3% (Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006).

From the analysis of the variable *time dedicated as a caregiver*, which has been identified as one of the key factors within the field of care (Montgomery & Kosloski, 2000), we observed an average of dedication slightly higher than that shown by Martín-Carrasco, Domínguez-Panchón, González-Fraile, Muñoz-Hermoso, and Ballesteros (2013). With respect to the three categories within this variable, it is worth noting how close our results

are to those of Kuhn, Fulton, and Edelman (2003) regarding the percentage of caregivers with fewer than 60 months of dedication.

For *psychological well-being*, coincidences were observed for all the scales referenced in the study by Oliva, Mendizábal, and Asencio (2013), which includes a sample with a high percentage (73.2%) of Spanish caregivers of more than 66 years old. When comparing our data for this variable with those reported by Donoso and Almagiá (2013) on slightly younger primary caregivers (48.8 years old on average), we also observed lower means for all the scales, with the exception of *positive relations* and *personal growth*. Such observations may be associated with the more solitary context in which the care tasks of their study's participants were framed (caregivers of patients with terminal cancer). Therefore, the caregivers in the mentioned study experienced lower personal growth, probably due to less stable health condition of their relatives, and a more stressful reality. Regarding the time of *involvement in self-care*, we were not able to compare the data obtained with those of other researchers who have analysed this same variable in primary caregivers (Boise, Congleton, & Shannon, 2005; Kuhn et al., 2003; Savundranayagam & Brintnall-Peterson, 2010; Won, Fitts, Favaro, Olsen, & Phelan, 2008), since these studies accounted for the dedication to the practice of some physical activity on the one hand, and relaxation strategies/stress management, on the other. Among these studies, we highlight the research by Won et al. (2008), who stated that 42.7% of caregivers devoted *1 hr or more per week* to physical activity and 25.8% who spent it on relaxation. With regard to psychological well-being and the general characteristics of the care situation, we only observed significant data among the *time dedicated as a caregiver* and the *positive relations* and *personal growth* scales, in a way that the participants providing continuous care for a longer time had more positive relations and a higher perception regarding their own evolution and positive learning. This result is consistent with that reported by Fernández-Lansac and Crespo (2011), who found that many caregivers described personal growth experiences derived from this role.

The data found between the scale of psychological well-being, *environmental mastery* and the *perceived burden*, are consistent with the results of other research on caregivers that have shown negative relationships between this scale, being one of the two most connected to the 'subjective' well-being scales, and perceived stress (Donoso & Almagiá, 2013). With regard to the perceived burden, a variable that stands out in

research linked to the field of care, we have not observed significant results for any other scale of well-being, nor for the other variable that is the focus of our study: the time dedicated to self-care. We believe that this result can be explained based on what was postulated by Pope, Giger, Lee, and Ely (2017), who suggested that personal characteristics might play a role in explaining the different relationship between perceived stress and self-care behaviours observed in their research, in contrast to evidence from previous investigations (Lu & Wykle, 2007). Such characteristics can influence them to relate differently to the role of caregiver, to stress, health and, consequently, to the prioritisation of self-care. Among these characteristics would be included the capacity to rethink challenges as opportunities, resources and resilience, optimism and the personal commitment to well-being. This possible influence on self-care postulated by Pope et al. (2017), has been confirmed in our research regarding the more eudaimonious view of well-being.

In addition to supporting the well-known connections to personal autonomy (Matsui & Capezuti, 2008; Wysocki et al., 2006), our findings support the importance of regular self-care behaviours for other aspects of personal significance. It is also possible to state that the results evidenced are consistent with what was propounded by Lawton, Moss, Winter, and Hoffman (2002), on the need for older adults to have 'personal projects' that structure their daily activities, whether health-related, intellectual or recreational, as long as they are related to increased well-being. Similarly, Villar, Triadó, Solé, and Osuna (2006) postulated that the important thing is not so much that older adults remain active, but that the activity they carry out is of high personal significance. Ogilvie (1987) also emphasised the importance of time spent on truly meaningful activities rather than just the amount of activities performed. Regarding the importance of this time spent on self-care, our results generally determined higher levels of psychological well-being among caregivers who, spending more than 3 hr a week, were highly committed to this habit. Other research on caregivers have also supported the existence of positive relationships between psychological well-being and engagement, which, understood as the involvement or tendency to become involved in various activities, social and institutional relationships, is at the same time an important component of a resilient personality (Donoso & Almagiá, 2013).

The evidence for the scales of psychological well-being more linked to the subjective perspective (*self-acceptance* and *environmental mastery*) and the time of *involvement in self-care*, coincides, to a certain extent, with the result found by Oliva et al. (2013). These authors found higher scores for adults who did physical exercise on a regular basis as well as higher values in *self-acceptance* and *purpose in life* in the participants who considered it important to care for and monitor their health.

Based on these findings, it is possible to consider the existence of a virtuous circle in the caregiver, whereby a greater involvement in self-care fosters their psychological well-being, which in turn fosters self-care regarding themselves and others. This idea would be consistent with conclusions that positive psychological well-being (life satisfaction, optimism) can encourage healthy behaviours by helping people deal with stress and manage challenges, persist in achievable goals or give up on other unattainable goals, and help people see through the consequences of short- and long-term actions (Rasmussen, Wrosch, Scheier, & Carver, 2006). That is, psychological well-being is not only associated with or is not the result of healthy behaviours, but it also derives from them and facilitates them. In this respect, it has been demonstrated how senior individuals with high levels of well-being are also physically more active than others reporting lower levels of well-being (Strine, Chapman, Balluz, Moriarty, & Mokdad, 2008).

This research work has some limitations that do not allow us to draw general conclusions from the results obtained. Among them is the limited sample size, common in the interventions carried out in this population, which we believe may have influenced the lack of significance of some variables.

Our study is also limited by not considering other important personal determinants such as economic income, that has been seen to influence the opportunities to develop a healthy lifestyle (Haslbeck et al., 2015; World Health Organization, 2013). We think that future lines of research can use socioeconomic data, together with that provided by some of the variables included in this work, to identify through machine learning the caregivers most likely to need socio-health support interventions. This opinion is supported by the conclusions of recent research, based on this new technology, carried out on a sample of caregivers of people with neurological pathology (Antoniadi, Galvin, Heverin, Hardiman, & Mooney, 2020). We also believe that it is of interest to develop future research on

interventions to promote self-care that seek to further encourage eudaimonic well-being and human potential.

5 CONCLUSIONS

This research, which was conducted on a sample of family caregivers with great similarities to those studied in most of the works published in our field, comprises of a preliminary analysis of two variables related to individual empowerment—the involvement in self-care and perceived well-being. The positive relationship between both, which we propose as a virtuous circle of self-promotion, has been shown not only from the more hedonic perspective (subjective), but also from the perspective of personal significance (psychological).

The results support other research in the field of self-care that intends to contribute to a further delimitation of the categories that we have outlined here. These ‘diagnostic labels’ could be used, among other possibilities, as a criterion for the selection of participants in socio-health interventions linked to the promotion of self-care or for the determination of their role in such interventions (educators, etc.). This procedure could be considered both for caregivers of dependent persons and for other groups of great interest in public health, such as patients of chronic disease.

Conflict of interest

The authors declare that they have no conflict of interest.

Informed consent

Informed consent was obtained from all individual participants included in the study.

REFERENCES

- Alonso-Babarro, A., Garrido-Barral, A., Matín-Martínez, M. A., & Francisco-Morejón, N. (2005). Evaluación de una intervención en cuidadores de pacientes con demencia (programa ALOIS) mediante una escala de calidad de vida. *Revista Española De Geriatria Y Gerontología*, 40, 40–45. [https://doi.org/10.1016/S0211-139X\(05\)75072-1](https://doi.org/10.1016/S0211-139X(05)75072-1)
- Antoniadi, A. M., Galvin, M., Heverin, M., Hardiman, O., & Mooney, C. (2020). Prediction of caregiver burden in amyotrophic lateral sclerosis: A machine learning approach using random forests applied to a cohort study. *British Medical Journal Open*, 10, e033109. <https://doi.org/10.1136/bmjopen-2019-033109>
- Boise, L., Congleton, L., & Shannon, K. (2005). Empowering family caregivers: The powerful tools for caregiving program. *Educational Gerontology*, 31, 573–586. <https://doi.org/10.1080/03601270590962523>
- Díaz, D., Rodríguez-Carvajal, R., Blanco, A., Moreno-Jiménez, B., Gallardo, I., Valle, C., & van Dierendonck, D. (2006). Adaptación española de las escalas de bienestar psicológico de Ryff. *Psicothema*, 18, 572– 577.
- Donoso, V. M., & Almagiá, E. B. (2013). Personalidad resistente, estrés percibido y bienestar psicológico en cuidadoras familiares de pacientes con cáncer terminal. *Psicología Y Salud*, 23, 153– 160.
- Draper, B. M., Poulos, C. J., Cole, A. D., Poulos, R. G., & Ehrlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. *Journal of the American Geriatrics Society*, 40, 896– 901. <https://doi.org/10.1111/j.1532-5415.1992.tb01986.x>
- Fernández-Lansac, V., & Crespo, L. (2011). Resiliencia, personalidad resistente y crecimiento en cuidadores de personas con demencia en el entorno familiar: Una revisión. *Clínica Y Salud*, 22, 21– 40. <https://doi.org/10.5093/cl2011v22n1a2>
- Ferrando, D. B., Canal, D. J., Motjé, N. B., Centellas, J. D., & Roura, A. D. (2006). Cambios en los cuidadores informales en cuanto a estilos de vida, relaciones y alteraciones de salud mental. *Revista De Enfermería De Salud Mental*, 2, 1– 8.
- Fuller-Jonap, F., & Haley, W. E. (1995). Mental and physical health of males caregivers of a spouse with Alzheimer's disease. *Journal of Aging and Health*, 7, 99– 118. <https://doi.org/10.1177/089826439500700105>
- Gallant, M. P., & Connell, C. M. (1997). Predictors of decreased self-care among spouse caregivers of older adults with dementing illnesses. *Journal of Aging Health*, 9, 373– 395. <https://doi.org/10.1177/089826439700900306>
- Haslbeck, J., Zanoni, S., Hartung, U., Klein, M., Gabriel, E., Eicher, M., & Schulz, P. J. (2015). Introducing the chronic disease self-management program in Switzerland and other German-speaking countries: Findings of a cross-border adaptation using a multiple-methods approach. *BMC Health Services Research*, 15, 576. <https://doi.org/10.1186/s12913-015-1251-z>
- Kramer, B., & Thompson, E. (2001). *Men as caregivers. Theory, research and service implications*. New York, NY Springer Publishing Company.

- Kuhn, D., Fulton, R. B., & Edelman, P. (2003). Powerful tools for caregivers: Improving self-care and self-efficacy of family caregivers. *Alzheimer's Care Quarterly*, 4, 189–200.
- Lawton, M. P., Moss, M. S., Winter, L., & Hoffman, C. (2002). Motivation in later life: Personal projects and well-being. *Psychology and Aging*, 17, 539–547. <https://doi.org/10.1037/0882-7974.17.4.539>
- López, J., & Crespo, M. (2007). Intervenciones con cuidadores de familiares mayores dependientes: Una revisión. *Psicothema*, 19, 72–80.
- López, J., & Crespo, M. (2008). Analysis of the efficacy of a psychotherapeutic program to improve the emotional status of caregivers of elderly dependent relatives. *Aging and Mental Health*, 12, 451–461. <https://doi.org/10.1080/13607860802224292>
- Losada-Baltar, A., Trocóniz, M. I. F., Montorio-Cerrato, I., Márquez-González, M., & Pérez-Rojo, G. (2004). Eficacia diferencial de dos intervenciones psicoeducativas para cuidadores de familiares con demencia. *Revista De Neurología*, 38, 701–708. <https://doi.org/10.33588/rn.3808.2003522>
- Lu, Y. Y., & Wykle, M. (2007). Relationships between caregiver stress and self-care behaviors in response to symptoms. *Clinical Nursing Research*, 16, 29–43. <https://doi.org/10.1177/1054773806295238>
- Mahoney, F. I., & Barthel, D. W. (1965). Functional evaluation: The Barthel Index. *Maryland State Medical Journal*, 14, 61–65.
- Martín, M., Salvadó, I., Nadal, S., Mijo, L. C., Rico Lanz, J. M., & Taussing, M. I. (1996). Adaptación para nuestro medio de la Escala de Sobrecarga del Cuidador (Caregiver Burden Interview) de Zarit. *Revista De Gerontología*, 6, 338–345.
- Martín-Carrasco, M., Domínguez-Panchón, A. I., González-Fraile, E., Muñoz-Hermoso, P., & Ballesteros, J. (2013). Effectiveness of a psychoeducational intervention group program in the reduction of the burden experienced by caregivers of patients with dementia. The EDUCA-II randomized trial. *Alzheimer Disease & Associated Disorders*, 28, 79–87. <https://doi.org/10.1097/WAD.0000000000000003>
- MATS. (2005). *Libro Blanco de la Dependencia*. Madrid, Spain IMSERSO, Ministerio de Trabajo y Asuntos Sociales.
- Matsui, M., & Capezuti, E. (2008). Perceived autonomy and self-care resources among senior center users. *Geriatric Nursing*, 29, 141–147. <https://doi.org/10.1016/j.gerinurse.2007.09.001>
- Montgomery, R. J. V., & Kosloski, K. D. (2000). Family caregiving: Change, continuity and diversity. In P. Lawton & R. Rubenstein (Eds.), *Interventions in dementia care: Toward improving quality of life* (pp. 143–171). New York, NY Springer.
- Muñoz-Cruzado y Barba, M., Fernández Martín, F., Barón López, F. J., Sánchez Guerrero, E., & Labajos Manzanares, M. T. (2008). Enfermedades psicósomáticas músculoesqueléticas en cuidadores de enfermos de Alzheimer: Necesidades de fisioterapia. *Fisioterapia*, 30(3), 116–121. [https://doi.org/10.1016/S0211-5638\(08\)72968-7](https://doi.org/10.1016/S0211-5638(08)72968-7)
- Navarro, P. S., Mederos, O. L., & Riera, A. L. (1999). Morbilidad en cuidadores de pacientes confinados en su domicilio. *Atención Primaria*, 24, 404–410.

- Ocaña, M. G., Vinuesa, M. D. S., Robles, R. G., & Castro, F. L. (2007). Repercusión familiar de la enfermedad de Alzheimer. *Revista De Enfermería Rol*, 30, 59– 64.
- Ogilvie, D. M. (1987). Life satisfaction and identity structure in late middle-aged men and women. *Psychology and Aging*, 2, 217– 224. <https://doi.org/10.1037/0882-7974.2.3.217>
- Oliva, A. J., Mendizábal, M. R. L., & Asencio, E. N. (2013). Análisis del bienestar psicológico, estado de salud percibido y calidad de vida en personas adultas mayores. *Pedagogía Social Revista Interuniversitaria*, 22, 153– 168. https://doi.org/10.7179/PSRI_2013.22.11
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18, 250– 267. <https://doi.org/10.1037/0882-7974.18.2.250>
- Ponce, C. R. (2010). El esfuerzo de cuidar a un ser querido y su impacto en la calidad de los cuidados y en la percepción de salud. *Cuidándote Digital*, 1, 6– 18.
- Pope, N., Giger, J., Lee, J., & Ely, G. (2017). Predicting personal self-care in informal caregivers. *Social Work in Health Care*, 56, 822– 839. <https://doi.org/10.1080/00981389.2017.1344755>
- Rasmussen, H. N., Wrosch, C., Scheier, M. F., & Carver, C. S. (2006). Self-regulation processes and health: The importance of optimism and goal adjustment. *Journal of Personality*, 74, 1721– 1748. <https://doi.org/10.1111/j.1467-6494.2006.00426.x>
- Rodríguez, I. M., Carrasco, A. M., Calvente, M. M. G., Cuadra, P. G., Jiménez, E. G., & Fernández, L. A. L. (2000). Cuidadores familiares de personas con enfermedad neurodegenerativa: Perfil, aportaciones e impacto de cuidar. *Atención Primaria*, 26, 139– 144. [https://doi.org/10.1016/S0212-6567\(00\)78630-6](https://doi.org/10.1016/S0212-6567(00)78630-6)
- Ryan, R. M., & Deci, E. L. (2001). On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. *Annual Review of Psychology*, 52, 141– 166. <https://doi.org/10.1146/annurev.psych.52.1.141>
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57, 1069– 1081. <https://doi.org/10.1037/0022-3514.57.6.1069>
- Savundranayagam, M. Y., & Brintnall-Peterson, M. (2010). Testing self-efficacy as a pathway that supports self-care among family caregivers in a psychoeducational intervention. *Journal of Family Social Work*, 13, 149– 162. <https://doi.org/10.1080/10522150903487107>
- Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12, 240– 249. <https://doi.org/10.1097/00019442-200405000-00002>
- Serrano-Aguilar, P. G., Lopez-Bastida, J., & Yanes-Lopez, V. (2006). Impact on health-related quality of life and perceived burden of informal caregivers of individuals with Alzheimer's disease. *Neuroepidemiology*, 27, 136– 142. <https://doi.org/10.1159/000095760>

- Slachevsky, A., Budinich, M., Miranda-Castillo, C., Núñez-Huasaf, J., Silva, J. R., Muñoz-Neira, C., Delgado, C. (2013). The CUIDEME study: Determinants of burden in Chilean primary caregivers of patients with dementia. *Journal of Alzheimer's Disease*, 35, 297–306. <https://doi.org/10.3233/JAD-122086>
- SMRC. (2018, April 28). Retrieved from <https://www.selfmanagementresource.com/>
- Strine, T. W., Chapman, D. P., Balluz, L. S., Moriarty, D. G., & Mokdad, A. H. (2008). The associations between life satisfaction and health-related quality of life, chronic illness, and health behaviors among US community-dwelling adults. *Journal of Community Health*, 33, 40–50. <https://doi.org/10.1007/s10900-007-9066-4>
- Villar, F., Triadó, C., Solé, C., & Osuna, M. J. (2006). Patrones de actividad cotidiana en personas mayores: ¿es lo que dicen hacer lo que desearían hacer? *Psicothema*, 18, 149–155.
- Won, C. W., Fitts, S. S., Favaro, S., Olsen, P., & Phelan, E. A. (2008). Community-based «powerful tools» intervention enhances health of caregivers. *Archives of Gerontology and Geriatrics*, 46, 89–100. <https://doi.org/10.1016/j.archger.2007.02.009>
- World Health Organization. (2013). *Global action plan for the prevention and control of NCDs 2013–2020*. World Health Organization. Retrieved from <https://apps.who.int/iris/handle/10665/94384>
- Wysocki, T., Harris, M. A., Buckloh, L. M., Wilkinson, K., Sadler, M., Mauras, N., & White, N. (2006). Self-care autonomy and outcomes of intensive therapy or usual care in youth with Type 1 diabetes. *Journal of Pediatric Psychology*, 31, 1036–1045. <https://doi.org/10.1093/jpepsy/jsj017>

TABLE 1. Level of psychological well-being and involvement in self-care of the caregivers

Variable	Category	
Psychological well-being of the caregiver	Self-acceptance ^a	21.46 ± 3.69
	Positive relations ^a	22.82 ± 4.56
	Autonomy ^a	28.60 ± 4.34
	Environmental mastery ^a	22.46 ± 3.53
	Purpose in life ^a	22.77 ± 4.20
	Personal growth ^a	27.08 ± 3.54
Involvement in self-care of the caregiver	Total time (min per week) ^b	97.3 ± 84.1
	According to the EPP	
	No time ^b	18 (40%)
	<30 min per week ^b	1 (2.2%)
	30–60 min per week ^b	0 (0%)
	1–3 hr per week ^b	6 (13.3%)
	>3 hr per week ^b	20 (44.4%)
	According to the new proposal	
	Not involved ^b	18 (40%)
Slightly involved (<3 hr per week) ^b	7 (15.6%)	
Highly involved (>3 hr per week) ^b	20 (44.4%)	

Abbreviation: EPP, The Expert Patients Programme—Stanford University.

^a Results expressed as M ± SD. ^b Results expressed as number of caregivers and percentage.

TABLE 2. Significance values for the comparison of mean values of the psychological well-being and time of involvement in self-care of the caregiver, according to the personal characteristics of the caregiver and general characteristics of the care situation

Personal characteristics of the caregiver								General characteristics of the care situation			
Variable	Category	Gender	Age	Family relationship	Level of Education	Regional context	Perceived burden	Time dedicated as caregiver	Caregiver responsibility	Caregiver occupation	Level of functional dependency of the relative
Psychological well-being of the caregiver	Self-acceptance	0.317 [U]	0.935 [U]	0.912 [H]	0.758 [H]	0.880 [U]	0.074 [H]	0.686 [H]	0.647 [U]	0.824 [U]	0.583 [H]
	Positive relations	0.768 [t]	0.385 [t]	0.430 [A]	0.973 [A]	0.836 [t]	0.309 [A]	0.045* [A]	0.443 [t]	0.462 [t]	0.459 [A]
	Autonomy	0.830 [t]	0.376 [t]	0.933 [A]	0.289 [A]	0.351 [t]	0.583 [A]	0.061 [A]	0.156 [t]	0.099 [t]	0.087 [A]
	Environmental mastery	0.826 [t]	0.838 [t]	0.830 [A]	0.669 [A]	0.267 [t]	0.020* [A]	0.072 [A]	0.440 [t]	0.576 [t]	0.346 [A]
	Purpose in life ²	0.570 [t]	0.569 [t]	0.467 [A]	0.902 [A]	0.783 [t]	0.100 [A]	0.322 [A]	0.183 [t]	0.569 [t]	0.809 [A]
	Personal growth	0.855 [U]	0.861 [U]	0.478 [H]	0.802 [H]	0.256 [U]	0.703 [H]	0.038* [H]	0.544 [U]	0.491 [U]	0.243 [H]
Time of involvement in self-care of the caregiver	Hours/week	0.152 [U]	0.378 [U]	0.665 [H]	0.816 [H]	0.009** [U]	0.174 [H]	0.130 [H]	0.711 [U]	0.920 [U]	0.362 [H]

Abbreviations: [A], ANOVA's test; [H], Kruskal–Wallis' test; [t], student's test; [U], Mann–Whitney's test.

* $p < 0.05$ (bilateral). ** $p < 0.01$ (bilateral)

TABLE 3. Analysis of the correlations of the sample population under study ($n = 45$) for the variable *time of involvement in self-care* and *psychological well-being* scales

Variable	Psicológicas well-being					
	Self-acceptance	Positive relations	Autonomy	Environmental mastery	Purpose in life	Personal growth
Time of involvement in self-care	+0.464 [S]**	+0.360 [S]*	+0.305 [S]*	+0.480 [S]**	+0.483 [S]**	+0.420 [S]**

[S], Spearman's correlation

* $p < 0.05$ (bilateral).

** $p < 0.01$ (bilateral).

TABLE 4. Comparison of the means of the *Psychological well-being* scales, between the different categories of *Involvement in self-care*

Psychological well-being	Involvement in self-care			<i>p</i> -value
	Not involved	Slightly involved	Highly involved	
Self-acceptance	20.44 ± 2.25 ^a	17.57 ± 2.76 ^b	23.75 ± 3.55 ^{a,b}	0.000**
Positive relations	21.27 ± 3.00	21.42 ± 6.07	24.70 ± 4.68	0.044*
Autonomy	27.05 ± 3.45 ^a	27.14 ± 4.74	30.50 ± 4.37 ^a	0.028***
Environmental mastery	20.61 ± 3.29 ^a	22.00 ± 1.63	24.30 ± 3.38 ^a	0.003***
Purpose in life	21.16 ± 3.22 ^a	19.71 ± 4.19	25.30 ± 3.67 ^a	0.000***
Personal growth	25.50 ± 3.03 ^a	26.42 ± 2.76	28.75 ± 3.61 ^a	0.017**

* Significant at $p < 0.05$ (bilateral).

** significant differences in at least two mean values ($p < 0.05$), indicating the superscript letters significant differences ($p < 0.05$), based on Kruskal–Wallis' test for independent samples.

*** significant differences in at least two mean values ($p < 0.05$), based on ANOVA, indicating the superscript letters significant differences ($p < 0.05$), based on Tukey's pair comparison test.