



DOCENCIA - INVESTIGACIÓN

Overload and pain in perceived caregivers of dependent elder

Sobrecarga y dolor percibido en cuidadoras de ancianos dependientes

*Villarejo Aguilar, L., **Zamora Peña, MA., ***Casado Ponce G.

*Dip Nursing. Master in Research and Innovation in health care and quality of life for Jaen Univ. Primary Care Nurse. Andalusian Health Service. E-mail: luisvillarejo@hotmail.es **Dip Nursing. Nurse Practitioner. Andalusian Health Service. ***Dip Nursing. Primary Care Nurse. Andalusian Health Service.

Palabras clave: sobrecarga; cuidadora; dolor; dependiente; anciano.

Keywords: overload; caregiver; pain; dependent elderly.

ABSTRACT

Objectives: To evaluate the subjective overload and perceived pain in caregivers of dependent elderly, and to determine if the intensity of perceived pain is associated with the caregiver overload.

Material and methods: A transversal study. Variables: age, sex, family relationship, living with the patient, educational level, time as a caregiver, paid work, Caregiver Stress Index (IEC) and pain intensity (VAS). Descriptive and inferential statistical analysis: Student t test, Pearson r and ANOVA, as appropriate.

Results: IEC 6.58 ± 1.21 , 6.60 ± 1.21 EVA, EVA and IEC correlation $r = 0.571$, $p < 0.0001$; EVA time as a caregiver and $r = 0.340$, $p < 0.026$.

Conclusions: Carers of dependent elderly have high rates of resistance and pain perception caused by very nature of care required by elderly dependents. Is there a direct relationship between pain intensity and degree of overload of the caregivers.

RESUMEN

Objetivos: Evaluar la sobrecarga subjetiva y el dolor percibido en cuidadoras de ancianos dependientes y determinar si la intensidad del dolor percibido está asociado a la sobrecarga de la cuidadora.

Material y métodos: Estudio observacional, descriptivo transversal. Variables: edad, sexo, parentesco familiar, convivencia con el paciente, nivel educativo, tiempo como cuidador, trabajo remunerado, Índice de Esfuerzo del Cuidador (IEC) e intensidad del dolor (EVA). Análisis estadístico descriptivo e inferencial: Test T de Student, r de Pearson y ANOVA, según los casos.

Resultados: IEC $6,58 \pm 1,21$, EVA $6,60 \pm 1,21$; correlación EVA y IEC $r = 0,571$, $p < 0,0001$; EVA y tiempo como cuidadora $r = 0,340$, $p < 0,026$.

Conclusiones: Las cuidadoras de ancianos dependientes presentan elevados índices de sobrecarga y percepción del dolor provocada por propias características de los cuidados que requieren los ancianos dependientes. Existe una relación directa entre la intensidad del dolor y el grado de sobrecarga de las cuidadoras.

INTRODUCTION

Increased life expectancy and the progressive aging of the Spanish population have resulted in considerable increase of people with chronic illness and/or disabilities that cause dependence on others for Activities of Daily Living ⁽¹⁾. This need for outside help for the dependent person is generally assumed by their close family, particularly female members ⁽²⁾. The assistance provided by carers is generally constant, intense, prolonged, and deepens as conditions worsen ⁽³⁾. In many cases this goes beyond caring for the elderly dependent and testing the physical and mental capabilities of caregivers, causing a chronic stressor, known as caregiver burden or overload ⁽⁴⁾. Caregiver burden, as a process of stress, may have important consequences for physical and mental health of the caregiver and their welfare ^(4,5). However, one should not conceive of the impact of care only as physiological and emotional caregiver stress but it is also important to consider the significant negative impacts that an overburdened caregiver may have on the quality and continuity of the assistance provided to the dependent ⁽⁶⁾.

Several studies have found that the caregivers perceived their health as worse than the general population. The dimensions of health are perceived as more related to deficient vitality (energy or feelings of exhaustion), general health and bodily pain ^(7,8). Pain is a symptom that occurs in varying degrees of intensity, as with most health problems, but that in itself is not considered a disease. Pain is a complex sensory and emotional experience that is associated with actual or potential tissue damage (International Association for the Study of Pain -1986-). Universally present during the individual's life, it affects the quality of life of individuals and their caregivers, and can cause psycho-emotional consequences, plus social and economic problems. Besides the pain the likelihood of five health care utilization increases and imposes a significant burden on direct and indirect health costs. The pain continues to be undervalued and undertreated, knowledge about the magnitude of pain is essential to ensure a comprehensive approach and avoid or minimize the suffering of people in pain. In this regard, the Community of Andalusia has made a clear commitment to try to alleviate this problem with the implementation of the Andalusian Plan of Care for People with Pain that provides for a package of activities-redirecting devices, spaces and Relief, training and involvement of professionals, research support, which are considered adequate to meet the health needs raised by the problem of pain and improve care at all levels ^(9, 10).

In summary, the caregivers of dependent elderly people are often overloaded due to the characteristics of their patients, who require lots of care, who also often have physical problems like back and neck pain, plus the constant need for help with regards to going to the toilet, changing diapers, eating and also to incorporate fun into his/her daily life, etc., along with the aggravating circumstance that most of them are women over 50 years old, which increased back injuries plus the fact that they refuse to stop caring for the sick. This makes it important to assess pain in this population group to try to establish interventions and resources to detect and prevent this malaise that affects the quality of life of carers and their immediate surroundings.

The present study aims to evaluate the subjective overload and perceived pain in caregivers of dependent elderly, and to determine if the intensity of perceived pain is associated with the caregiver overload.

MATERIALS AND METHODS

An observational and descriptive cross-sectional study in the months from May to July 2010 was carried out. The study population consisted of elderly care that met the following inclusion criteria: informal caregivers of elderly dependents (I.Barthel <60) the portfolio of services including care of the elderly dependent on the BSA study, being over 18, a primary caregiver, having had longer than three months as a caregiver and having severe pain during the week preceding the interview or a chronic pain. The sampling procedure was intentional, leaving the sample set of 43 caregivers. The variables included in the study were age, sex, family relationships, living with the elderly, education, time as a caregiver, time spent per day, paid work, Caregiver Stress Index (IEC), intensity of pain. Data collection was done in the patient's home by semistructured interview and questionnaire completion, the overhead is measured by the IEC in Castilian and validated version consisting of 13 items with dichotomous responses (true or false), where each affirmative response's score was 1. A score of 7 or more suggests a high level of effort. Pain intensity was measured with Visual Analogue Scale (VAS) consisting of a Likert scale numbered from 0 to 10, where 0 is no pain and 10 the worst pain bearable. Statistical analysis was descriptive and inferential. The Student t test, Pearson r and ANOVA tests were used for bivariate analysis where appropriate. The participation of informal caregivers was voluntary and on informed consent previously requested to participate in the study.

RESULTS

Of the 43 caregivers, 39 were women (90.7%) and only 4 men (9.3%) with a mean age of 59.51 years ranging from 37-68 years old. The kinship was a 86% grade 1 family (spouse or child-as), 9.3% grade 2 families and 4.7% without kinship or consanguinity with the PP. 60.5% live with the patient and most are unemployed 76.7%.66.7% have primary education and have 3.39 years on average as a caregiver.

Table 1. Sociodemographic characteristics of caregivers.

VARIABLES	Percentage or mean (frequency)
Age (years)	59,51 ± 6,47
Sexo	
Men	9,3% (4)
Women	90,7% (39)
Relationship:	
Family of 1 degree	86%(37)
Grade 2 Family	9,3%(4)
Unrelated	4,7%(29)
Coexistence:	
Yes	60,5%(26)
Not	39,5(17)

Education:	
No education	
Primary education	16,3% (7)
Secondary education	66,7% (29)
Studied	14,0% (6)
	2,3% (1)
Paid work:	
Yes	23,3% (10)
Not	76,7% (33)
Caregiver time (years)	3,39 ± 1,81
Time (hours) devoted a day	15,54 ± 2,31

Overloading the caregivers' subjective measure with the IEC had a mean of 6.58 ± 1.21 , of which 48.9% had a high stress level. Current pain intensity was 6.60 ± 1.21 , ranging from 4 to 8 maximum pain perceived.

The correlational analysis showed a high association ($r = 0.571$, $p < 0.0001$) between the perceived pain (VAS) and the overhead of the caregiver (IEC). Likewise pain was positively correlated with time as a caregiver ($r = 0.340$, $p < 0.026$). With all other variables of the pain perceived by the caregivers not showing significant associations.

DISCUSSION

The profile of the average caregivers of the elderly dependent in the sample corresponds to a woman around 60 years old, immediate relative or partner of the dependent, with primary and economically without remuneration for work performed, the profile corresponds to the profile of carer reported in other studies^(5,11,12,13). Since the study was conducted on the population attending a city health center of medium size, the generalization of their findings and conclusions must be made with caution, although we believe they are representative and general, because the characteristics of our caregivers are similar to those described in other groups studied in the literature.

The overload felt by the caregivers was mostly high, 48.9% of caregivers had a high level of effort which aligns to those reported in other studies^(12,13,16), this data corresponds to the patients that require a significant amount of care, with high consumption of resources and significant economic and welfare costs. Knowing the degree of overload on the caregivers of the dependent elderly is important because it demonstrates its relationship to their quality of life⁽¹⁵⁾ and because there is evidence that can be diminished through different interventions^(15,16), with the caregivers who support greater overload potentially benefitting the most from such actions⁽¹⁷⁾. Most research on the negative consequences of informal care emphasizes the existence of some individual variety between caregivers regarding the burden and stress, given that not all caregivers respond in the same way to the same stress or the same levels of demand nor use the same resources to address them. In this regard, it stressed that there are individual differences among caregivers regarding burden and perceived stress.

In relation to the perceived pain the carers in the most severe pain were scored as > 6 , it is noteworthy that no caregiver reported a pain intensity between 0 and 4. In a recent study on

the perceived health of carers of Biscay, the carers are in more intense pain than the general Spanish population ^(18,19).

This shows a direct relationship between overload and perceived pain, caring for an elderly dependent becomes stress that impacts on the caregiver overload causing increased pain perception.

The relationship between time as caregivers and the perceived pain is also significant, time in charge of an elderly dependent is a determining factor of the physical health of the caregiver, leading to more vulnerability of the caregiver with greater presence of fatigue, muscle pain, back pain and headaches ⁽¹⁹⁾.

All of this highlights the need to promote multidisciplinary activities aimed at supporting carers, both preventive measures and support, especially when revision made on the subject shows the potential benefits ⁽²⁰⁾. There are previous reports on different types of interventions (training, psychobehavioral, support groups, respite newspaper, etc.) Made by different professionals (doctors, nurses, psychologists, multidisciplinary teams, etc.) These interventions have shown positive results in various aspects of both the person served and the caretaker (delayed patient institutionalization, reduced overhead perceived by the caregiver and the impact of this overhead posed to the various areas of health, etc.) ⁽²¹⁾, interventions need to be adapted to the characteristics and needs of each caregiver ⁽²²⁾.

In conclusion we note that the carers of elderly dependents in the present study live with high levels of overload and perception of pain caused by very nature of care required by elderly dependents, plus a direct relationship between pain intensity and overload of the caregivers.

REFERENCES

- (1) Romero L, Martín E, Navarro JL, Luengo C. El paciente anciano: demografía, epidemiología y utilización de recursos. En: Sociedad Española de Geriátría y Gerontología. Tratado de geriatría para residentes. Madrid: Marketing & Comunicación; 2006. p. 33-46.
- (2) Jenson, J. y Jacobzone, S. (2000). Care allowances for the frail elderly and their impact on women care-givers. Labour Market and Social Policy – Occasional Papers nº 41. Paris: OECD; Directorate for Education, Employment, Labour and Social Affairs; Employment, Labour and Social Affairs Committee.
- (3) Casado, D. y López, G. (2001). Vejez, dependencia y cuidados de larga duración. Situación actual y perspectivas de futuro. Colección Estudios Sociales, núm. 6. Barcelona: Fundación La Caixa.
- (4) Zarit, S.H. (2002). Caregiver's Burden. En S. Andrieu y J.P. Aquino: Family and professional carers: findings lead to action. Paris: Serdi Edition y Fondation Médéric Alzheimer.
- (5) García, M.M.; Mateo, I. y Maroto, G. (2004). El impacto de cuidar en la salud y la calidad de vida de las mujeres. *Gaceta Sanitaria*, 1B (Supl 2), 83-92.
- (6) Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, Dane K, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA* 2002;287:2090-7.
- (7) Blanes, L., Carmagnani, MIS., & Ferreira, LM. (2007). Health-related quality of life of primary caregivers of persons with paraplegia. *Spinal Cord*, 45, 399-403.
- (8) Patti, F., Amato, MP., Battaglia, MA., Pitaro, M., Russo, P., Solaro, C., et al. (2007). Caregiver quality of life in multiple sclerosis: a multicentre Italian study. *Multiple Sclerosis*, 13, 412-419.

- (9) Álvarez González, J; Ayuso Fernández, A; Caba Barrientos, F; et al. Plan andaluz de atención a las personas con dolor : 2010 – 2013. Sevilla : Consejería de Salud, 2010.
- (10) Proceso asistencial integrado dolor crónico no oncológico, 2006. Sevilla. Consejería de Salud. Disponible en <http://www.csalud.juntaandalucia.es/procesos/documentos.asp?idp=184>.
- (11) IMSERSO (2002). Las personas mayores en España. Informe 2002: Datos estadísticos estatales y por comunidades autónomas. Vol. I. Madrid: Ministerio de Trabajo y Asuntos Sociales, Secretaría General de Asuntos Sociales, Instituto de Migraciones y Servicios Sociales, Observatorio de personas mayores.
- (12) Alonso A, Garrido A, Díaz A, Casquero R, Riera M. Perfi I y sobrecarga de los cuidadores de pacientes con demencia incluidos en el programa ALOIS. Aten Primaria 2004; 33:61-68.
- (13) Badia X, Lara N, Roset M. Calidad de vida, tiempo de dedicación y carga percibida por el cuidador principal informal del enfermo de Alzheimer. Aten Primaria 2004; 34:170-177.
- (14) Moreno-Gaviño L, Bernabeu-Wittel M, Alvarez-Tello M, Rincón- Gómez M, Bohórquez-Colombo P, Cassani-Garza M et al. Sobrecarga sentida por la fi gura del cuidador principal en una cohorte de pacientes pluripatológicos. Aten Primaria 2008; 40:193-198.
- (15) Martin M, Salvado I, Nadal S, Miji LC, Rico JM, Lanz P et al. Adaptación para nuestro medio de la escala de sobrecarga del cuidador (caregiver burden interview) de Zarit. Rev Gerontol 1996; 6 338-346.
- (16) Artaso B, Goñi A, Biurrun A. Cuidados informales en la demencia: predicción de sobrecarga en cuidadoras familiares. Rev Esp Geriatr Gerontol 2003; 38:212-218.
- (17) Zabalegui A, Navarro M, Cabrera E, Gallart A, Bardallo MD, Rodríguez E et al. Eficacia de las intervenciones dirigidas a cuidadores principales de personas dependientes mayores de 65 años: una revisión sistematica. Rev Esp Geriatr Gerontol 2008; 43:157-166.
- (18) Diputación Foral de Bizkaia. Las personas cuidadoras en Bizkaia.2010.
- (19) Jeanfaivre V, Diviné C, Akalin MN, Anacharsis F, Montagne A, Le Parco JC. A survey of pain prevalence at Albert-Chenevier Hospital. Comparison of patient, caregivers and physician assessments. Ann Med Interne (Paris). 2003;154:499-508.
- (20) Torres MP, Ballesteros E, Sánchez PD. Programas e intervenciones de apoyo a los cuidadores informales en España. Gerokomos 2008; 19:9-15.
- (21) Bliss J. What do informal carers need from district nursing services?. Br J Community Nurs 2006; 11:251-256.
- (22) López J, Crespo M. Intervenciones con cuidadores de familiares mayores dependientes: una revisión. Psicothema 2007; 19:72-80.