

Simposio: Cuidados profesionales y familiares de adultos mayores dependientes: El papel de la Psicología Positiva en la Prevención del Burnout y la Promoción de la Salud para el área temática Salud Mental

Apoyo social y resiliencia como predictores de la calidad de vida relacionada con la salud en cuidadores familiares de personas con demencia

Pablo Ruisoto¹, Lúdia Serra², Ana Nieto-Carracedo³, Bernardino Fernández-Calvo⁴, Jesús Rivera-Navarro²

¹Universidad Pública de Navarra, España

²Instituto Piaget de Almada, Portugal

³Universidad de Salamanca

⁴Universidad de Córdoba

Declaración de conflicto de intereses y financiación

No existe conflicto de interés.

Financiación:

Estudio financiado por el Ministerio de Ciencia e Innovación (ref: CSO2010-20721).

Pablo Ruisoto está financiado por la Unión Europea– NextGenerationEU, Convocatoria de ayudas para la Recualificación del Sistema Universitario Español para 2021-2023 en la Universidad Pública de Navarra (Resolución 1402/2021).

Contextualización

Los cuidadores familiares de las personas con demencia experimentan importantes niveles de estrés, inherentes a la naturaleza de los cuidados que proporcionan, que pueden comprometer su salud física y mental (Beadle y Gildford, 2020; Campos et al., 2019).

La calidad de vida física y mental de los cuidadores familiares de personas con demencia se ha podido deteriorar por la reciente situación de pandemia (Eckardt, 2020).

Correspondence

Caregivers of people with severe mental illness in the COVID-19 pandemic

Studies have shown that severe mental illness is often associated with substantial pressures on family members of the person with mental illness, especially those individuals who have a caregiving role. Caring for someone with a severe mental health disorder can compromise the caregiver's own physical and psychological health, and can lead to psychological distress, anxiety, depression, and post-traumatic stress disorder.¹ There have been reports of caregivers experiencing loss and grief, sadness, fatigue, emotional exhaustion, sleep disturbance, burnout, blame, guilt, social isolation, and financial hardship, combined with the consequences of stigma attached to mental illness.^{2,3} However, families can play an important role in supporting people with mental illness in the community, during their treatment, and are a key part of their social network. Unfortunately, the circumstances of caregivers are not always a focus of attention of mental health services worldwide.

The current COVID-19 pandemic can affect not only people with mental health disorders,⁴ but also their family and caregivers. Urgent attention is needed to ensure that the appropriate support is provided. The pandemic could lead to substantial deterioration of family functioning caused by the unimaginable pressure inflicted by COVID-19 restrictions and precautions; in particular, the increased pressure on caregivers might result in an imbalance in the demand for resources and disputes between family members. As caregiving is not a free resource, having a mental illness during a global pandemic could have a huge effect on the entire family system—eg, financially, socially, and interpersonally—especially when

combined with the impact of larger-scale effects of the pandemic on socioeconomic conditions. There is scarce research on the effect of COVID-19 on caregivers⁵ and I am concerned that the current public health messaging might be leaving out this important at-risk population who are underutilised in the treatment of people with mental illness. To care for patients with mental health disorders on a global scale during this pandemic, the importance of caregivers needs to be recognised more than ever before. The health-care community cannot afford to lose the aid of caregivers, engagement with whom offers a unique opportunity to ensure healthy lives and overall wellbeing for people with mental health disorders.

I declare no competing interests.

Jens Peter Eckardt
jpe@bedrepsykiatri.dk

Bedre Psykiatri, Videnscenter, Research Unit, Copenhagen 1201, Denmark

- 1 Onwumere J, Bebbington P, Kuipers E. Family interventions in early psychosis: specificity and effectiveness. *Epidemiol Psychiatr Sci* 2011; **20**: 113-19.
- 2 Saunders J. Families living with severe mental illness: a literature review. *Issues Ment Health Nurs* 2003; **24**: 175-98.
- 3 Gowers SG, Bryan C. Families of children with a mental disorder. In: Sartorius N, Leff J, Lopez-Ibor JJ, Maj M, Okasha A, eds. *Families and mental disorders: from burden to empowerment*. Hoboken, NJ: John Wiley & Sons, 2005: 127-59.
- 4 Yao H, Chen JH, Xu YF. Patients with mental health disorders in the COVID-19 epidemic. *Lancet Psychiatry* 2020; **7**: e21.
- 5 Holmes EA, O'Connor RC, Perry VH, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *Lancet Psychiatry* 2020; published online April 15. [https://doi.org/10.1016/S2215-0366\(20\)30168-1](https://doi.org/10.1016/S2215-0366(20)30168-1).

Beadle, J.N., & Gifford, A. (2020). Psychological, brain, and hormonal factors associated with caregiver compassion fatigue, burnout, and stress. *Alzheimer's & Dementia*, 16.

Campos-Puente, A., Avargues-Navarro, M. L., Borda-Mas, M., Sánchez-Martín, M., Aguilar-Parra, J. M., & Trigueros, R. (2019). Emotional Exhaustion in Housewives and Alzheimer Patients' Caregivers: Its Effects on Chronic Diseases, Somatic Symptoms and Social Dysfunction. *International journal of environmental research and public health*, 16(18), 3250. <https://doi.org/10.3390/ijerph16183250>

Eckardt J. P. (2020). Caregivers of people with severe mental illness in the COVID-19 pandemic. *The lancet. Psychiatry*, 7(8), e53. [https://doi.org/10.1016/S2215-0366\(20\)30252-2](https://doi.org/10.1016/S2215-0366(20)30252-2)

Hiyoshi-Taniguchi, K., Becker, C.B., & Kinoshita, A. (2018). What Behavioral and Psychological Symptoms of Dementia Affect Caregiver Burnout? *Clinical Gerontologist*, 41, 249 - 254.

Objetivo

Analizar los potenciales predictores de la calidad de vida asociada con la salud física y mental en cuidadores familiares de personas con demencia.

Métodos

Participantes:

Muestra total compuesta por 283 cuidadores familiares de personas con demencia

La edad media de los cuidadores fue $M = 58.62 \pm 12.45$ años y de los pacientes, $M = 77.97 \pm 6.02$ años.

Diseño y procedimiento

Estudio transversal multicéntrico, aprobado por el Comité de Bioética de la Universidad de Salamanca y desarrollado según las directrices establecidas en la Declaración de Helsinki. Todos los participantes dieron su consentimiento informado escrito.

Métodos

Medidas:

Variables de la persona con demencia:

Variabes sociodemográficas: edad, sexo, educación

Variabes clínicas:

- Severidad de demencia (Clinical Dementia Rating (CDR) scale, Hughes et al., 1982)
- Grado de dependencia funcional (Pfeffer Scale, Olazarán, et al., 2005)
- Psicopatología (Neuropsychiatric Inventory- Brief Questionnaire Form, NPI-Q, Kaufer et al., 2000)
- Deterioro cognitivo (Informant Questionnaire Cognitive Decline in the Elderly, IQCODE; S-IQCODE, Spanish version, Morales et al., 1992).

Variables del cuidador:

Variabes sociodemográficas (edad, sexo, educación) y de cuidado (relación con paciente y duración del cuidado)

- Nivel de sobrecarga (Zarit Burden Interview, Zarit et al., 1986)
- Sintomatología de ansiedad y depresión (Goldberg Anxiety and Depression Scale, Goldberg et al., 1988)
- Optimismo fundado (Battery of Generalized Expectancies of Control Scales, BEEGC, Palenzuela et al., 1997)
- Apoyo social percibido (Duke-Unc Social Support Questionnaire, de la Revilla et al., 1991)
- Resiliencia (Connor-Davidson Resilience Scale, CD-RISC, Connor et al., 2003)
- Caregiver Abuse Screen (CASE)(Reis et al., 1995; Pérez-Rojo et al., 2015)
- Calidad de vida (World Health Organization Quality of Life-Brief, WHOQOL-BRIEF; The WHOQOL Group, 1998; Lucas-Carrasco, - 2012)
- Calidad de vida asociada con la salud física y mental (Short Form Survey, SF12v2, Schmidt et al., 2012)

Resultados | Características asociadas con calidad de vida

Relacionadas con el cuidador

Edad del cuidador (SF)

Ser esposas/esposos (vs hijas/hijos) (SF)

Ser mujer (vs hombre) (SM)

Bajo nivel educativo (SF)

Número de horas de cuidado/día(SF, SM)

Nivel de sobrecarga (SF, SM)

Apoyo social (SF, SM)

Resiliencia (SF, SM)

Family caregivers		Physical Health (SF12v2)	Mental Health (SF12vs)
<i>Age</i>	59.9 ±14.6	-.356** ^b	-.039 (n.s.) ^b
<i>Sex</i>			
Women	186 (65.7) ^a	47.91 + 20.08	41.99 + 16.22
Men	91 (34.3) ^a	54.49 + 18.17	49.09 + 13.70
<i>Relationship</i>			
Son/daughter	115 (40.6) ^a	56.67 + 16.46	45.37 + 16.64
Husband/wife	157 (55.5) ^a	37.81 +19.29	42.95 +13.19
Other	11 (3.9) ^a	54.68 + 18.85	38.02 +23.91
<i>Education level</i>			
Primary education	92 (32.5) ^a	39.05 + 19.05	41.42 + 15.81
Secondary education	103 (36.4) ^a	48.27 + 19.92	43.75 + 16.77
Higher education	82 (29.0) ^a	59.62 + 15.12	46.63 + 15.00
<i>Previous relationship</i>			
Food-very good	264 (92.7) ^a	48.75 + 19.11	43.94 + 16.78
Other		49.92 + 19.87	44.01 + 15.76
<i>Time of care (years)</i>	3.9 ± 3.3	.664 (n.s.) ^b	.652 (n.s.) ^b
Less of 2 years		51.91 +18.47	47.83 + 15.09
From 2 to 4 years		48.25 + 20.21	40.90 + 16.53
More tan 4 years		50.20 + 20.50	43.81 + 15.39
<i>Caregiving per day (hours)</i>	12.6 ± 8.3	-.174** ^b	-.188* ^b
<i>Burden (Zarit)</i>	9.4 ± 6.7	-.246** ^b	-.510** ^b
<i>Resilience (Connor-Davidson)</i>	73.9 ± 13.7	.317** ^b	.256** ^b
<i>Social support (DUKE)</i>	27.64 ± 7.9	.164** ^b	.293** ^b

Note. ^a Values indicate means and standard deviations. ^a Frequencies and percentages between parenthesis are shown for nominal variables. ^b Pearson correlations (* $p < .005$; ** $p < .001$).

Resultados | Características asociadas con calidad de vida

Relacionadas con la persona con demencia

Síntomas conductuales (SM)

Deterioro cognitivo (SF, SM)

Nota: independientemente del resto de características clínicas del paciente.

People with dementia			
<i>Age</i>	83.9 ± 5.4	-.025 (n.s.) ^b	-.075 (n.s.) ^b
<i>Sex</i>			
Men	100 (30.7) ^a	40.13 + 20.56	41.29 + 16.65
Women	217 (66.6) ^a	54.99 + 17.22	45.47 + 15.25
<i>Education level</i>			
Men			
Women			
<i>Type of dementia</i>			
Alzheimer's disease	268 (82.2) ^a	50.83 + 19.34	43.97 + 15.99
Other dementias ^c	419(15.0) ^a	44.94 + 21.08	44.14 + 15.34
<i>Marital status</i>			
Married	166 (58.7) ^a	57.08 + 17.94	42.30 + 16.88
Widow, single, separated	15 (31.3) ^a	44.85 + 19.42	45.15 + 15.06
<i>Living status</i>			
Alone	26 (9.2) ^a	53.22 + 16.90	40.86 + 17.97
Several people (1 house)	247 (87.3)	49.07 + 20.01	44.43 + 15.63
Several houses (rotation)	10 (3.5) ^a	69.68 + 2.20	39.06 + 19.88
<i>Deterioro cognitivo (Informant test, S-IQCODE)</i>	97.9 ± 20.6	-.120* ^b	-.195* ^b
<i>Síntomas conductuales (Neuropsychiatric Inventory, NPI)</i>	9.1 ± 6.2	-.108 (n.s.) ^b	-.254** ^b
<i>Grado dependencia funcional (Pfeffer Scale, FAQ)</i>	24.3 ± 9.3	-.072 (n.s.) ^b	-.075 (n.s.) ^b
<i>Grado dependencia (actividades básicas) (Barthel Index)</i>	3.8 ± 2.1	-.024 (n.s.) ^b	-.089 (n.s.) ^b
Independence or mild dependency		50.72 + 19.65	44.39 + 17.09
Moderated dependency		51.48+19.93	45.99 + 14.68
Severe dependency		46.86 + 19.85	41.74 + 14.66

Note. ^a Values indicate means and standard deviations. ^a Frequencies and percentages between parenthesis are shown for nominal variables. ^b Pearson correlations (* $p < .005$; ** $p < .001$). ^c Vascular dementia, frontotemporal dementia, secondary dementia and dementia with unknown etiology.

Conclusiones

La calidad de vida (física y mental) de los cuidadores familiares de las personas con demencia está asociada con la sobrecarga, horas de cuidado, y grado de deterioro cognitivo del paciente.

La calidad de vida física es peor en los cuidadores más jóvenes, y la mental en los cuidadores de pacientes con más síntomas conductuales.

La calidad de vida (física y mental) de cuidadores familiares de las personas con demencia es significativamente mejor en quienes cuentan con mayor apoyo social siendo más resilientes.

Discusión

Los resultados son consistentes con previos estudios y destacan la importancia de:

1. La **sobrecarga** como principal factor de riesgo para la salud en cuidadores de personas con demencia (Alves et al., 2019; Gérain y Zech, 2020; Hiyoskhi et al., 2018), identificando otros factores de vulnerabilidad como: menor edad, mayor número de horas de cuidado (generalmente mujeres), y mayor deterioro cognitivo y síntomas conductuales en el paciente.

2. El **apoyo social** como principal factor de protección ante el estrés y promotores de la salud en los cuidadores familiares (Dempsey y Baago, 1998; Schoenmakers et al., 2010; Lee et al., 2021a; Lee et al., 2021b) y **resiliencia**; estos elementos son necesarios para el diseño de intervenciones eficaces dirigidas a mejorar la salud en este colectivo (Ducharme et al., 2011) y la calidad de sus cuidados (Sheikh, Javed, Ijaz, Leyba, Barrett, & Dunn, 2022).

Alves, L., Monteiro, D. Q., Bento, S. R., Hayashi, V. D., Pelegri, L., & Vale, F. (2019). Burnout syndrome in informal caregivers of older adults with dementia: A systematic review. *Dementia & Neuropsychologia*, 13(4), 415–421.

Dempsey, M., & Baago, S. (1998). Latent grief: The unique and hidden grief of carers of loved ones with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 13, 84 - 91.

Ducharme, F.M., Lévesque, L., Lachance, L., Kergoat, M., Legault, A., Beaudet, L., & Zarit, S.H. (2011). "Learning to become a family caregiver" efficacy of an intervention program for caregivers following diagnosis of dementia in a relative. *The Gerontologist*, 51 4, 484-94 .

Gérain, P., & Zech, E. (2020). Do informal caregivers experience more burnout? A meta-analytic study. *Psychology, Health & Medicine*, 26, 145 - 161.

Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Supporting the dementia family caregiver: The effect of home care intervention on general well-being. *Aging & Mental Health*, 14, 44 - 56.

Lee, K., Archer, B., Cox, K., & Pickering, C.E. (2021). Sources of Positivity in the Daily Life of Family Caregivers of Persons with Dementia. *Innovation in Aging*, 5, 655 - 655.

Lee, J., Baik, S., Becker, T.D., & Cheon, J.H. (2021). Themes describing social isolation in family caregivers of people living with dementia: A scoping review. *Dementia*, 21, 701 - 721.

Sheikh, A. B., Javed, N., Ijaz, Z., Leyba, K., Barrett, E., & Dunn, A. (2022). Easing dementia caregiver burden, addressing interpersonal violence. *The Journal of Family Practice*, 71(1), E1–E8.